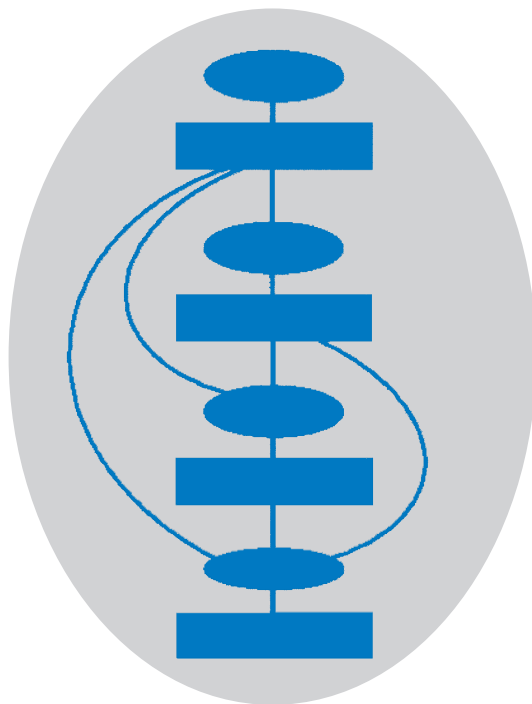




Guidance on Cancer Services

Improving Outcomes for People with Skin Tumours including Melanoma

The Manual



February 2006

Developed by the National Collaborating Centre for Cancer

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Foreword

*Improving Outcomes for
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Foreword

This guidance manual is the latest in the *Improving outcomes in cancer* series and the second produced by the National Collaborating Centre for Cancer (NCC-C). In particular there appeared to be a need to formalise and standardise the ways in which patients with the most common skin tumours and precancerous conditions are managed and in which health professionals in primary care are involved in their care. It was also clear that a group of patients with tumours that are rarer or more difficult to treat need to have easy access to very specialised professional care and a range of highly technical treatments.

We hope that the guidance will point the way to important changes in the structure and organisation of care for patients with skin cancer and will lead to genuine improvement in the outcomes for a very large group of patients who have perhaps been overlooked in the recent changes in the provision of cancer services in the NHS.

I would like to thank all the members of the Guidance Development Group (GDG), especially the chair, Dr Julia Verne, and the lead clinician, Dr Dafydd Roberts, for their hard work and commitment during the two years we have been collaborating on this project. I am also very grateful to all the expert advisers who have contributed (Appendix 5.4), and to the health professionals and patients around the country who participated in the survey of patient experiences (see Evidence Review) and gave us additional and very useful information.

Dr Fergus Macbeth

Key recommendations

Key recommendations

- Cancer networks should establish two levels of multidisciplinary teams – local hospital skin cancer multidisciplinary teams (LSMDTs) and specialist skin cancer multidisciplinary teams (SSMDTs). All health professionals who knowingly treat 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.
- People with precancerous skin lesions should be either treated entirely by their GP or referred for diagnosis, treatment and follow-up to doctors working in the community who are members of the LSMDT/SSMDT. If there is any doubt about the diagnosis, people with precancerous lesions should be referred directly to their local hospital skin cancer specialist, normally a dermatologist, who is a member of the LSMDT/SSMDT. Where appropriate, follow-up of these patients may be undertaken by their own GP.
- Patients with low-risk basal cell carcinomas (BCCs) (see ‘Glossary of terms’, Appendix 6, for definitions) should be diagnosed, treated and followed up by doctors working in the community as part of the LSMDT/SSMDT (usually a GP with a special interest in dermatology [GPwSI]), or a local hospital skin cancer specialist, normally a dermatologist, who is a member of the LSMDT/SSMDT and to whom they have been directly referred. Where there is doubt about the lesion being low or high grade, the patient should be referred directly to the LSMDT/SSMDT.
- All patients with a suspicious pigmented skin lesion, with a skin lesion that may be a high-risk BCC, a squamous cell carcinoma (SCC) (see ‘Glossary of terms’, Appendix 6, for definitions) or a malignant melanoma (MM), or where the diagnosis is uncertain, should be referred to a doctor trained in the specialist diagnosis of skin malignancy, normally a dermatologist, who is a member of either an LSMDT or an SSMDT.
- Cancer networks should ensure, through the skin cancer network site-specific group, that LSMDTs and SSMDTs work to network-wide agreed protocols for:

- referral
- review of patient care by the multidisciplinary team (MDT)
- management and audit of services for precancerous lesions and skin cancer services.

They should also ensure provision of ongoing education for all healthcare professionals about this very common group of tumours.

- The follow-up of patients after treatment should be jointly agreed between patient and doctor. After appropriate instruction, patients with low-risk disease will normally practise self-examination but follow-up may be offered in a community setting where appropriate. Patients with a high risk of recurrence of their skin cancer or of new primary cancers should normally be followed up in hospital but should still be instructed in self-examination and provided with written and photographic information.
- All patients and carers should have access to high-quality information, in an appropriate style and format, about their condition and its management and about access to relevant support services.
- Skin cancer network site-specific groups should follow protocols covering the management of high-risk groups or those with special needs such as transplant patients, those with genetic predisposition to skin cancer, patients with rare skin tumours (including cutaneous lymphoma), and children and young people.
- Data collection on skin cancer including cancer registration should be improved to adequately describe the epidemiology and service implications of the increasing incidence of skin cancer. This should be facilitated by new developments in information technology to enable more accurate and timely provision of this information.
- Commissioners of cancer services should create an infrastructure for well-conducted research to take place in order to contribute to the skin cancer evidence base in epidemiology, treatment and management.

Introduction

The National Institute for Health and Clinical Excellence (NICE) commissioned the National Collaborating Centre for Cancer (NCC-C) to develop guidance on the organisation of services for skin tumours for use by the NHS in England and Wales. This follows referral of the topic by the Department of Health (DH) and Welsh Assembly Government.

This guidance provides recommendations for service provision that are based on the best available evidence, or consensus positions, and supports current national initiatives outlined in *The NHS Cancer Plan* [1], the Calman–Hine Report [2], the Cameron Report [3], the *Manual for Cancer Services* in England [4] and the *Wales National Standards for Skin Cancer Services* [5]. The guidance manual also refers to other NICE service guidance documents including *Referral guidelines for suspected cancer* [6], *Improving supportive and palliative care for adults with cancer* [7], *Improving outcomes in children and young people with cancer* [8], *Improving outcomes in haematological cancers* [9], *Improving outcomes in gynaecological cancers* [10] and *Improving outcomes in urological cancers* [11]. This guidance has also taken into consideration the recommendations contained in the NICE service guidance on *Improving outcomes in head and neck cancers* [12] and *Improving outcomes for people with sarcoma* [13].

The scope of this guidance

This manual provides service guidance for commissioners and providers of services for patients with skin cancer and precancerous lesions of the skin. It provides guidance on service configuration for the diagnosis and management of these skin lesions and for the support of patients and carers through this process. The full scope is reproduced in Appendix 2. It does not include guidance on prevention or early detection. However, as the epidemiology of skin cancer and evidence from Australia suggest, in the long term the most effective way to reduce the impact of skin cancer on the population and the NHS will be through reduction of exposure to ultraviolet (UV) radiation, particularly sun, combined with increased population awareness of signs and symptoms of cancer. The evidence base and recommendations for action on prevention, increasing awareness and

early detection have been published in the Health Development Agency document titled *Cancer prevention: A resource to support local action in delivering The NHS Cancer Plan* [14]. This service guidance manual applies equally to services for adults, and services for children and young people with ‘adult-type’ skin tumours (see section on children in ‘Management of special groups’).

The challenges of providing services for patients with skin cancer

The incidence of all types of skin cancer has increased steadily over the past decade, as a result of social changes, including increased UV light exposure from both sun and artificial sources. There are significant regional and sub-regional variations in the incidence and mortality of both MM and non-melanoma skin cancer (NMSC) across England and Wales, with the highest incidence and mortality rates in the South West region of England [15]. Both latitude and ethnic composition of the population are important correlates of incidence at local authority level. It has been suggested that, because of historic patterns of UV exposure, affluent women are at the greatest risk of developing MM and men from lower socio-economic groups are at the greatest risk of developing NMSC. The social and economic determinants underlying levels of UV exposure, the adoption of preventive measures and the early recognition of skin cancer are complex and have probably been changing over the last decade. This will lead to a complex interaction between socio-economic status and the risk of developing and of presenting with skin cancer.

Skin cancers and precancerous lesions are, as a group, very different from most other groups of cancers. Skin cancers are very common. They constitute the most common group of cancers in the UK with approximately 60,000 new cases registered in England and Wales each year, accounting for 20% of all cancer registrations [16]. Currently registration of skin cancer is neither standardised nor complete and this is likely to result in a significant underestimate of the total number of skin cancers diagnosed each year. There are many types of skin cancer, but three types are responsible for more than 95% of all skin cancers. These are basal cell carcinoma (BCC), squamous cell carcinoma (SCC) and malignant melanoma (MM). BCC and SCC are often grouped together as non-melanoma skin cancer (NMSC). Many patients will present with more than one skin cancer. The total number of skin cancers has more than doubled in 10 years but this may reflect improved coding.

Examples of rare types of skin cancers are listed in Appendix 1. In the South West region of England, with a population of 6 million, 87 rare cancers from the list were diagnosed in 2002 [17].

The aetiology of most skin cancers is well understood, and a proportion of these should be largely preventable. It is recognised that UV light plays an important part in the aetiology of most types of skin cancer although this is not a direct linear relationship for BCC and MM. Because the skin is easy to see, precancerous lesions and cancers can frequently be identified at an early stage by patients themselves. The majority of skin cancers are associated with a low risk of death, and this has implications for the organisation of follow-up. Skin cancers account for less than 2% of the total cancer deaths each year and the majority (about 80%) of these deaths are from MM [16]. Treatments for precancerous lesions and skin cancers are usually relatively simple, involving removal or destruction of the lesion. Some patients will, however, require extensive and longer-term treatment and their specific needs should be addressed. A number of high-quality, multidisciplinary clinical guidelines that detail the management of specific cancers and precancerous lesions are already available, produced by the British Association of Dermatologists (BAD) [18]. A large proportion of patients with precancerous lesions and some with NMSC can be safely managed in primary care if the guidance outlined in this manual and the BAD clinical guidelines are adhered to.

Very little information has been available to date on the self-perceived needs of skin cancer patients in relation to service provision. In order to address this problem, specific work was commissioned by the GDG to elicit the views of patients with skin cancer on current service provision. This study was performed by a team of qualitative researchers from the Department of Social Medicine, University of Bristol, and is available in the Evidence Review.

The main challenges are inadequate data on which to base estimates of service need and a lack of standardised infrastructure in both primary care and hospitals for the care of skin cancer patients. This section outlines what is known about the epidemiology of skin cancer that could be used to plan local services and the recommendations for improvements in data collection and quality. The subsequent sections contain guidance on the organisation of services to provide quality-assured services to meet the needs of patients and carers.

The epidemiology of skin cancers and precancerous lesions

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Background

Skin cancer registration

Across England and Wales the cancer registries have adopted different practices for the registration of skin cancers. On the whole, first diagnoses of MM are likely to be comprehensively registered but staging is available on only 77.4% of cases in England and 35.2% of cases in Wales [19]. Subsequent metachronous (or new primary) MM in the same patient may not be recorded because of local policy and/or because of confusion between recurrence and new primary lesions. With respect to NMSCs, some registries do not register BCCs at all. Others register only the first of each skin cancer type diagnosed in a patient and so they do not record metachronous cancers of the same histological type. Even for those cancer registries that do, there is difficulty sometimes in differentiating between recurrences and new primaries. The coding of rare cancers is, in general, poor and for this reason the Office for National Statistics (ONS) does not routinely publish data by morphology code for the rare skin cancers. A proportion of NMSCs are treated, by destruction, without histology; details of these cancers may not reach the cancer registries, especially if they are treated in primary care. These factors will all contribute to a significant underestimate of the number of skin cancers being diagnosed and treated. This will affect estimates of:

1

- the number of new cases diagnosed each year
- the number of new patients diagnosed each year
- the risk of presenting with multiple primaries
- the risks of developing metachronous lesions
- the incidence of rare skin cancers
- survival and prevalence.

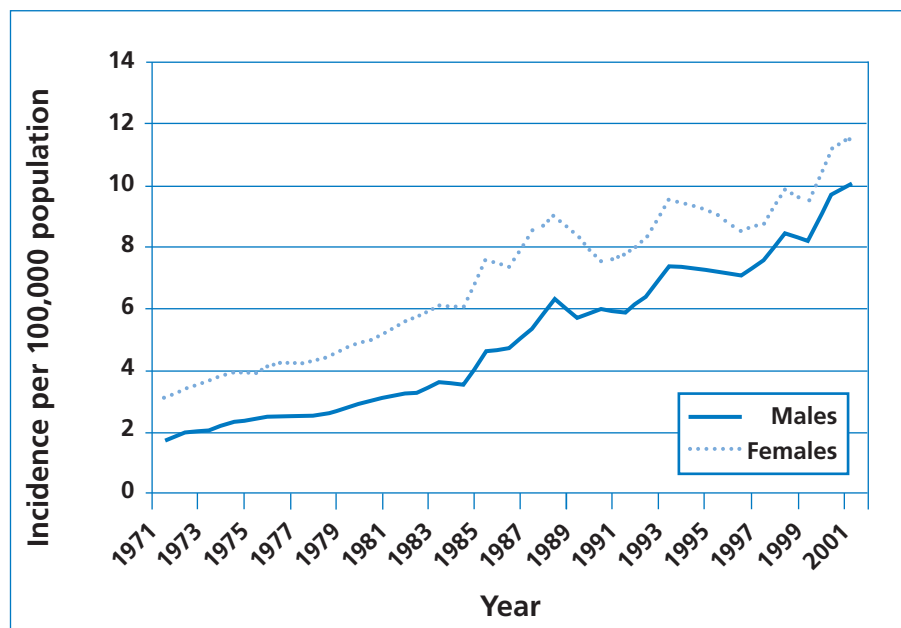
Cancer registries do not register precancerous lesions of the skin and the number of these treated will greatly outnumber the cancers. The only estimates of the population incidence or prevalence of precancerous skin lesions come from population-based surveys.

The estimate of 60,000 new cases of skin cancers in England and Wales each year [16] is therefore likely to be a significant underestimate and does not include BCCs. One of the few studies published in the UK suggests that the true annual incidence could be over 125,000 new cases of NMSC annually in England and Wales. This would mean that a district general hospital (DGH) serving a population of 250,000 would treat about 625 new cases per year and a typical general practice, serving a population of 10,000, would see about 25 new NMSC cases each year. Despite these limitations, cancer registry data can be used to look at trends in incidence, mortality and survival, and variations in these by sex, age and region of the country.

Malignant melanoma

MM, although far less common (around 10% of skin cancers) than NMSC [16], is the major cause of death from skin cancer [16] and is more likely to be accurately reported and diagnosed than NMSC. MMs most commonly develop on intermittently exposed sites, on the back in males and the lower leg in females. In 2001 there were 6432 new cases of MM registered in England and Wales [20]. MMs are more common in women than in men. The age-standardised incidence of MM has been steadily increasing over the past three decades in both males and females with rates of 11.7 (females) and 10.1 (males) per 100,000 population by 2001 (Figure 1) [17].

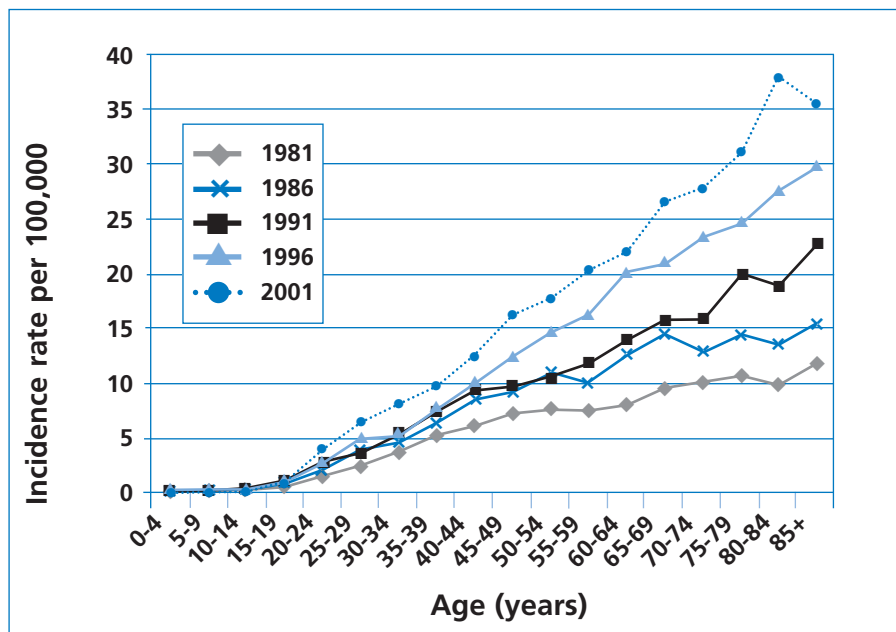
Figure 1. Age standardised incidence of MM, England and Wales, 1971–2001





The incidence of MM increases with age in both men and women, rising steadily in both sexes from age 15 years onwards. It is the third most common tumour in the 15–39 age group [16]. The median age of diagnosis of MM in men is 62 years and in women 60 years [16]. In Figure 2 the changes in age-specific incidence rates between 1981 and 2001 are shown. The incidence rate has increased in each age group age 15 and older over the last two decades.

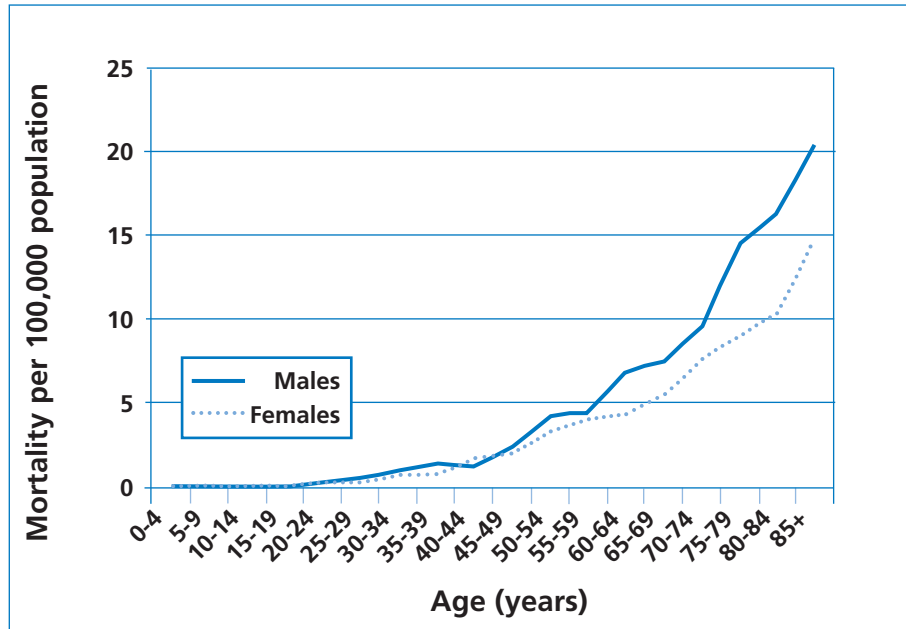
Figure 2. Incidence of MM, all persons England and Wales, 1981–2001



There are approximately 1500 deaths from MM in England and Wales each year [16]. MM is a significant cause of cancer mortality in the 15–39 age group and the number of potential years of life lost is greater than for some other cancers.

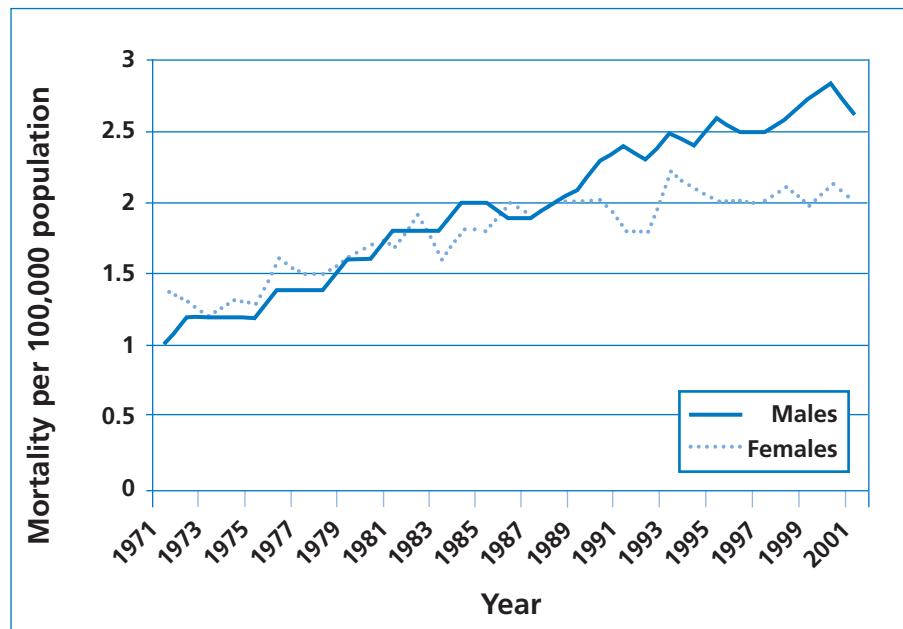
The age-specific mortality rates for MM of the skin are higher in men than in women in the older age groups, and the increase in mortality with age mirrors the increase in incidence. The 2001 provisional figures indicated that the peak mortality at ages 85 years and older would reach 20 in men and 15 in women per 100,000 population [17] (Figure 3).

Figure 3. Mortality from MM, England and Wales, 2001



Male mortality rates from MM have risen steadily since 1970 and had more than doubled by 2001 (1.0/100,000 in 1970, 2.6/100,000 in 2001). Mortality in females increased across the same time period, but to a smaller extent (from 1.4/100,000 to 2.0/100,000 population) [17] (Figure 4).

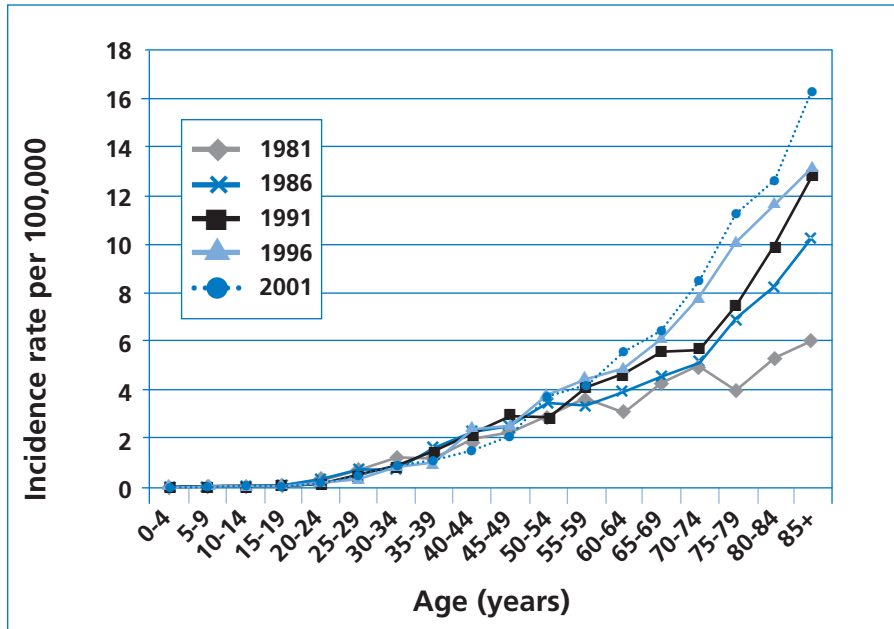
Figure 4. Age-standardised mortality from MM, England and Wales, 1971–2001



While age-specific mortality rates for MM peak in the oldest age groups, there appears to be an increasing mortality rate over the past two decades that is particularly discernible in the over-60 age groups [17] (Figure 5).



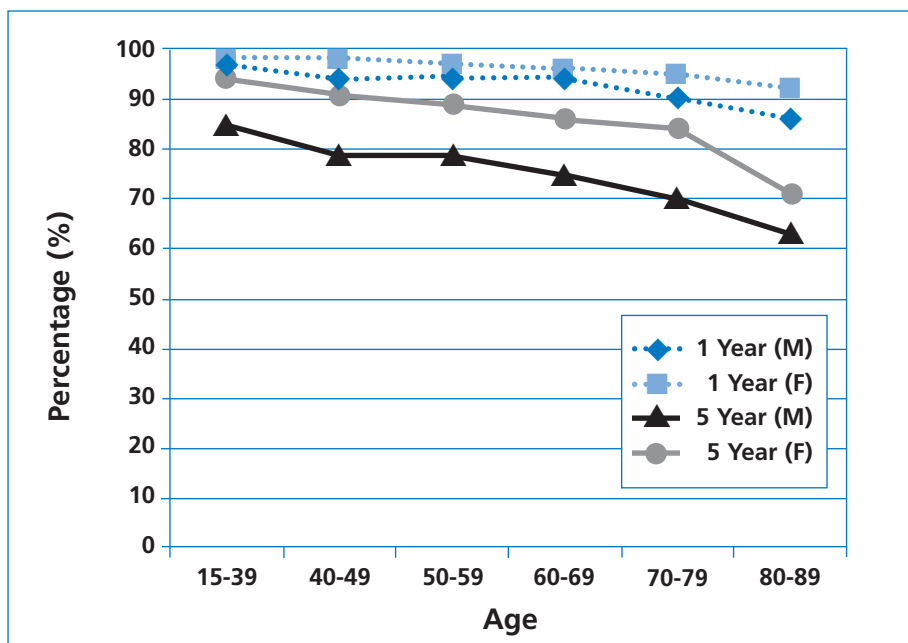
Figure 5. Mortality from MM, England and Wales, 1981–2001



In contrast, the survival of MM patients has improved over time. In England and Wales the 5-year survival for MM in men has increased from 72.9% for cancers diagnosed between 1991 and 1995 to 76.5% for those diagnosed between 1996 and 1999. For the same time periods 5-year survival in women increased from 85.1% to 87.3%. Both of these increases are statistically significant [21].

In the UK as a whole the overall 5-year survival rate is 73% in men and 85% in women. Survival among MM patients decreases with increasing age and is lower among males [21] (Figure 6).

Figure 6. Survival in MM patients, 2001, for males (M) and females (F)



Survival in MM is strongly correlated with the depth of invasion at diagnosis, commonly known as the Breslow thickness [22, 23].

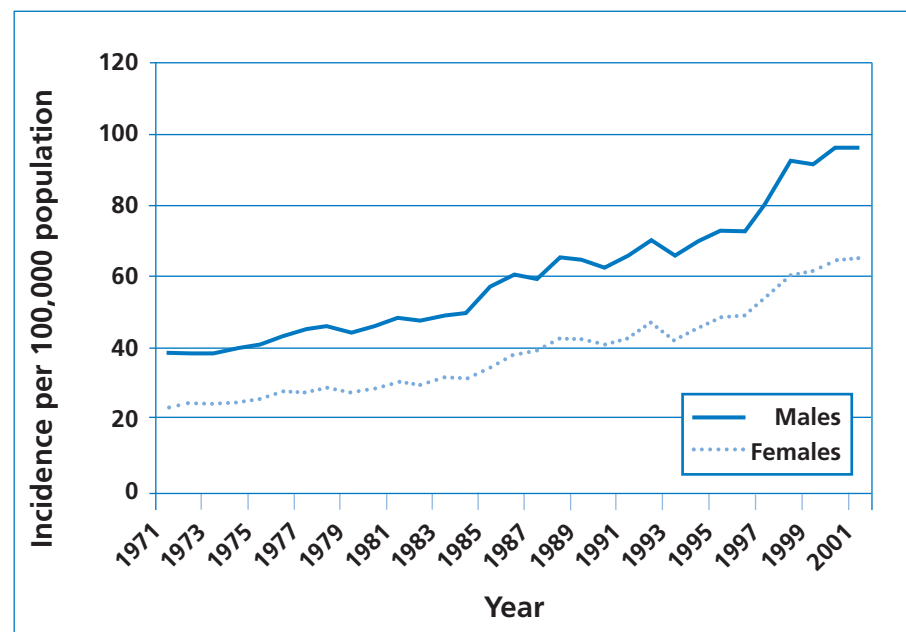
Non-melanoma skin cancers (NMSC)

NMSCs are the most common cancers in the UK. Although an estimated 50,000 cases were registered in 1999 across England and Wales [16] there is likely to be significant under-reporting of cases.

NMSCs are most common in older age groups. The median age at diagnosis is 72 years for males and 74 years for females [16]. The most common places for NMSCs to develop are on the exposed body parts such as the face, neck, ears, forearms and hands. While these are rarely fatal, they can result in considerable morbidity.

The age-standardised incidence has continued to increase steadily in both sexes since the 1970s but has remained higher in males. By 2001, comparative rates were 65 in females and 96 in males per 100,000 population [20] (Figure 7).

Figure 7. Age-standardised incidence of NMSC, England and Wales, 1971–2001



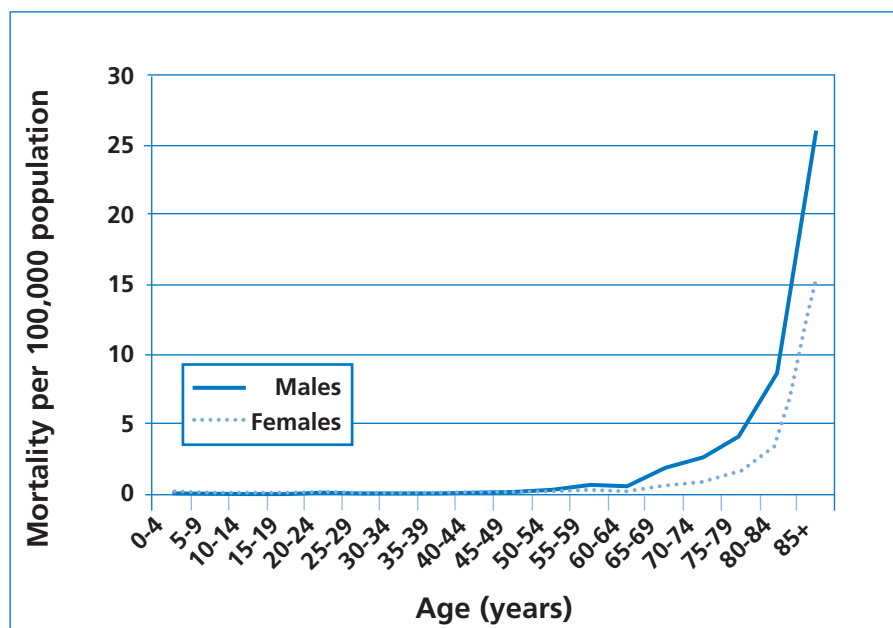
Incidence rates increase with age in males and females from age 25 years onwards. Numbers are higher in males relative to females; in 2001 the incidence reached 1108 per 100,000 in males and 612 per 100,000 in females among those aged 85 years and older [17] (Figure 8).

Figure 8. Incidence of NMSC, England and Wales, 2001



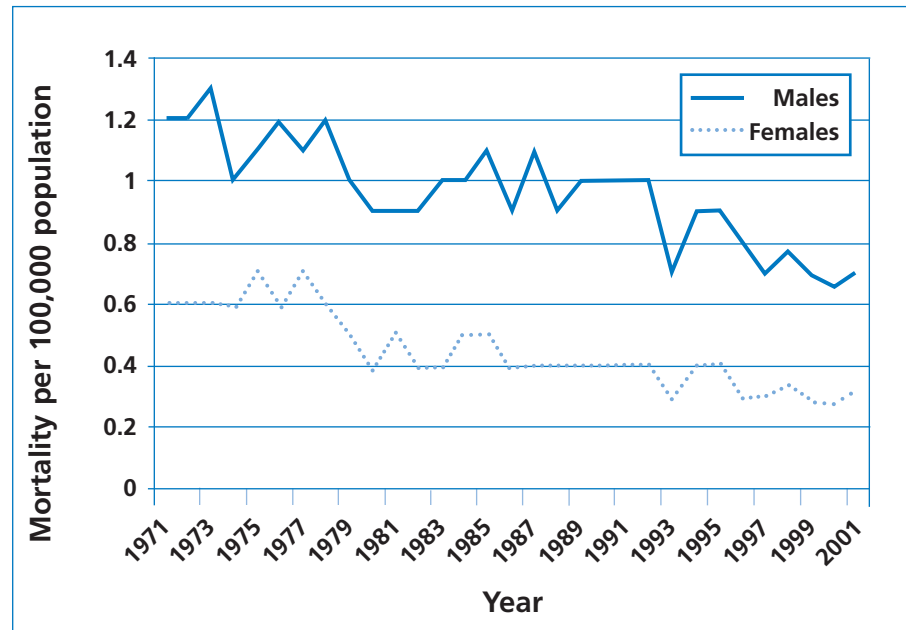
There are about 400 deaths per year from NMSCs [16]. The rates for 2001 show that mortality from NMSC remains low in those individuals younger than 50 years of age. Mortality in men increases steadily from age 60 years onwards peaking at 26 per 100,000 population in those aged 85 years or older. Female mortality rates begin to rise steeply from age 70 years and peak at 15 per 100,000 population in the same age group [17] (Figure 9).

Figure 9. Mortality from NMSC, England and Wales, 2001



In contrast to MM, from 1970 to 2001 the age-standardised mortality rates declined in both men and women. The recorded mortality halved in females (0.6 to 0.3 per 100,000 population) and nearly halved in men (1.2 to 0.7 per 100,000 population). Mortality rates recorded in 2001 are higher in men than in women, the figure for men having remained almost consistently double that for women since 1970 [16] (Figure 10).

Figure 10. Age-standardised mortality from NMSC, England and Wales, 1971–2001



Multiple primaries

Many skin cancer patients develop multiple cancers of different histological types, and it is not uncommon for a patient to present with any combination of MM, SCC and BCC or to present with one type and develop another subsequently. As described previously, cancer registration practices vary significantly, making an accurate assessment of the risk of presenting with or developing metachronous cancers difficult.

Rare skin tumours

It is estimated that approximately 90 skin cancers that fall into the rare skin cancer group definition are diagnosed each year in the South West region of England [17], which had a population of approximately 4.94 million in 2001. The types are listed in Appendix 1.

Risk factors for skin cancer

As skin cancer has become more common over the past few decades, it has become a greater public health problem. While mortality is relatively low, a significant demand on health services results from the associated morbidity. NMSCs on the head and neck in particular are numerically a significant cause of morbidity. In 1992 the White Paper *Health of the Nation* [24] included a target to halt the year-on-year increase in incidence of skin cancer by 2005; at that time there were about 28,000 cases of skin cancer registered each year. This target has not been reached, as the incidence of skin cancer continues to increase.

Strategies for prevention are essential to avoid skin cancer affecting an increasing percentage of the population. The most important risk factor for skin cancer development is UV exposure, both natural and artificial. Higher risk of MM is associated with a family history (seen in 1% of UK patients), multiple moles and fair, sunburn-susceptible skin types. Exposure to UV was acknowledged in *The NHS Cancer Plan* [1] as a risk that needs to be addressed. The most effective strategy for preventing skin cancer is the avoidance of exposure to UV light from the sun and artificial sources.

Epidemiology clearly identifies overexposure to sunlight in people with sensitive skin types as the main risk factor. High-profile campaigns to reduce UV exposure, such as the Slip, Slap, Slop campaign in Australia [25], have reversed the rising incidence trends there, but in the UK at present very few primary care trusts (PCTs) in England and local health boards (LHBs) in Wales have a strategy for reducing skin cancer incidence. However, Cancer Research UK have initiated their SunSmart campaign [25], funded by the UK Health Department. Insufficient promotion of the hazards of exposure at a national level was raised as a concern by skin cancer patients in a recent survey conducted for this guidance (see Evidence Review). Other environmental factors such as arsenic are now rare risk factors for the development of skin cancer.

A small proportion (less than 2%) of skin cancers develop in people with a strong genetic predisposition. The most common conditions are Gorlin's syndrome and familial melanoma. Xeroderma pigmentosum (XP) is a rare but very high-risk genetic condition. Another well-described risk factor is immunosuppression, especially following organ transplantation. These groups are at increased risk from UV exposure and should all be given prevention advice. As for many patients in these high-risk groups the development of skin cancer is inevitable, services for early detection and treatment need to be tailored to their specific needs. The risk to these groups of patients is described and guidance on service provision given in the chapter on the 'Management of special groups'.

Patterns of service provision

The only routinely available sources of data on health service use for skin cancer collated at a national level are Hospital Episodes Statistics (HES) for England and the Patient Episode Database in Wales (PEDW). These data capture inpatient admissions and day case procedures but not outpatient activity. This means that they only record a small proportion of the overall NHS activity for skin cancer patients as many are managed in primary care, and of those managed in hospital most will be managed as outpatients. This has been confirmed by a study undertaken in two trusts to compare the numbers of skin cancer cases reported by histopathology and HES activity for the period 1995–2002 (see Evidence Review). Only 36% of MM and 41% of NMSC pathology data were reflected in the HES data. This contrasts with most other cancer types where the majority of patients will have at least one hospital admission.

Coding variations between hospitals for the classification of skin cancer procedures as outpatient or day cases limit the usefulness of the data for local comparisons. However, as there is no other source, HES and PEDW data still give some important insights into trends in service provision and who delivers these services for the most severe cases.

Using these data, a gradual increase in the rate of episodes of care for MM and NMSC patients is seen in England and Wales [26] (Figures 11 and 12). The figures for 1997 reflect inadequate data capture processes resulting from coding changes at that time.

Figure 11. Rates of episodes of inpatient care for MM, England (E) and Wales (W)

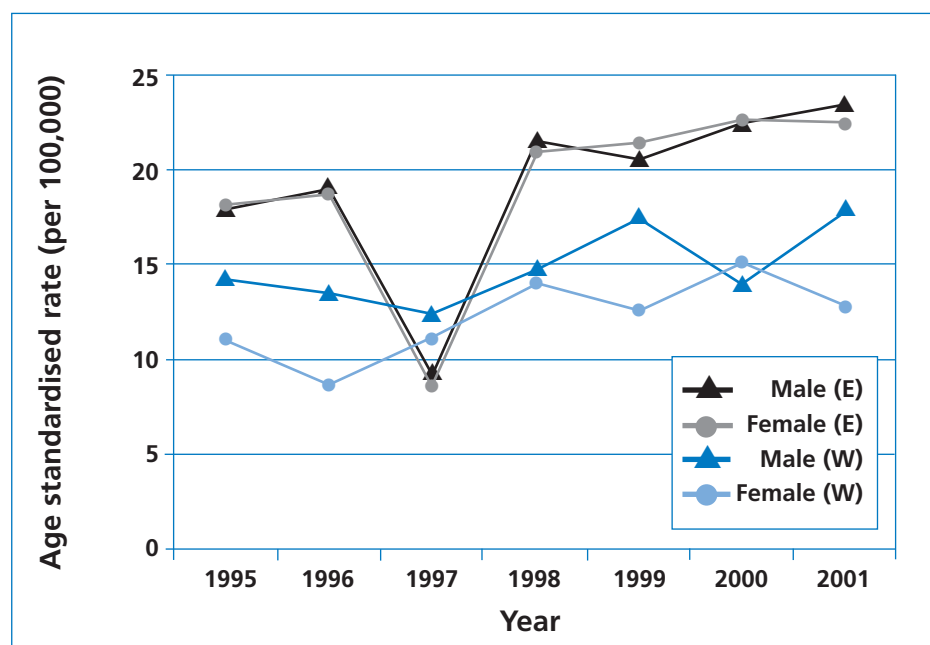
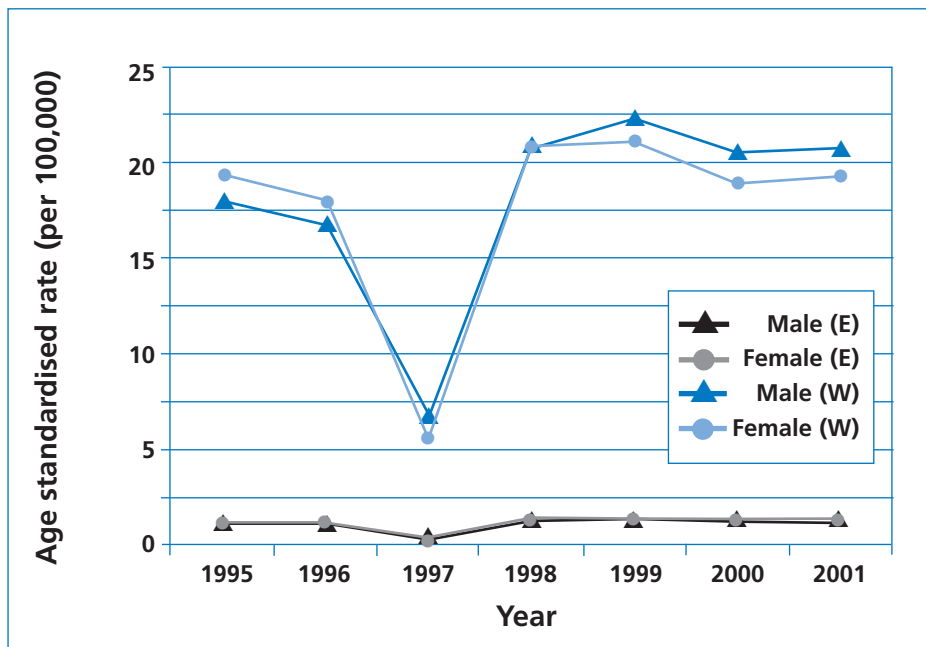




Figure 12. Rates of episodes of inpatient care for NMSC, England (E) and Wales (W)



Incidence of MM episodes of care from 1993 to 2000, by the then English NHS region of treatment, is included in the Evidence Review. Almost all regions have experienced a significant increase in MM incidence. A greater increase in episodes of care is observed for males than for females.

Similarly, looking at NMSC episodes of care from 1993 to 2000 by English NHS region of treatment, all regions have experienced a significant increase. The exception to this trend has been London, with a significant decrease in episodes of care observed, which may possibly reflect a shift in activity to outpatient clinics or primary care clinics [26].

One of the striking characteristics of inpatient skin cancer services is the range of doctors involved in treatment and care, together with a variety of different patient pathways and experiences. Figure 13 shows that over time, as a result of specialisation, dermatologists and plastic surgeons have taken on a greater proportion of skin cancer work. Table 1 demonstrates a steady increase since 1993 in the proportion of patients treated by a dermatologist in their first episode of care in hospital. It should be noted, however, that data on episodes of care will not include those patients treated in an outpatient clinic [26].

Figure 13. Number of episodes of inpatient care for MM, by selected specialties, England 1991–2000

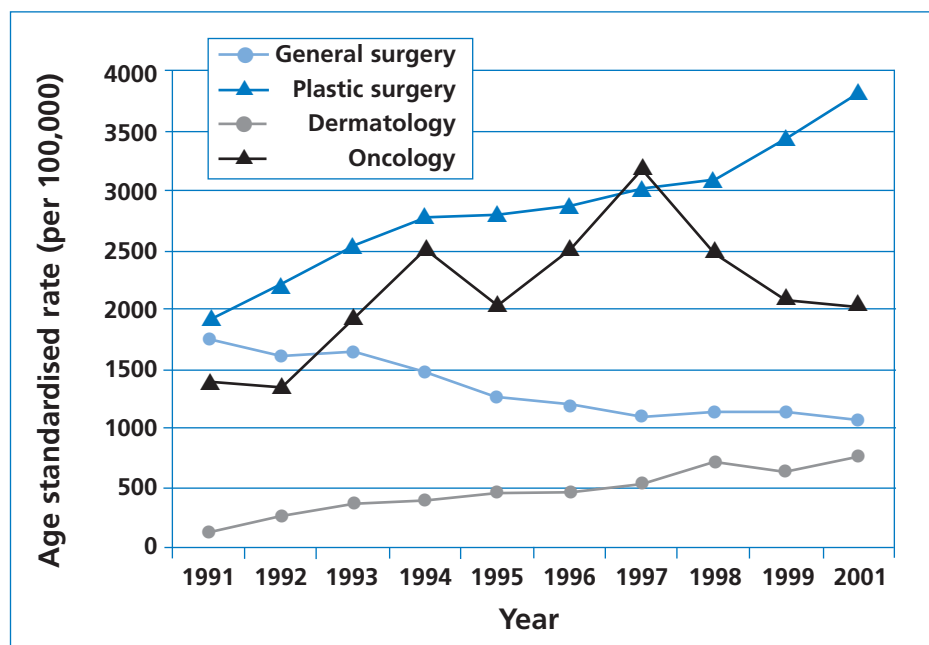


Table 1. Proportion of patients treated by dermatologists

Year	MM (%)	NMSC (%)
1993	9.2	16.5
1994	6.8	22.5
1995	7.1	23.6
1996	6.4	25.5
1997	10.0	28.9
1998	14.7	31.7
1999	13.8	31.1
2000	16.3	30.4

Specialist and supraregional specialist services

At present there is a paucity of services at regional and supraregional level that specialise in the care of high-risk or special groups, for example transplant patients, those with genetic predisposition to skin cancer, those with rare skin tumours (including cutaneous lymphoma) and young people with skin cancer.

Two-week wait data

Urgent skin cancer referrals made using the 2-week wait criteria in England, which reflect MM and SCC outpatient workloads (but exclude precancerous lesions and BCC), accounted for 12.4% of all 2-week wait referrals during the fourth quarter of 2004/2005 [27]. Skin is the third-commonest group of cancers to be referred after breast and lower gastrointestinal cancers. An overview of 52 audit studies of skin cancer referrals under the 2-week rule found that MM and SCC account for 10–12% of the referrals, with the remainder found to be benign lesions [28].

Primary care activity

There is a paucity of evidence regarding the current levels of management and/or biopsy of skin tumours in primary care. Following the first stakeholder consultation of this guidance, the results of nine audits from NHS trusts in England (see Evidence Review) were submitted to the NCC-C and gave an indication of the wide range of activity in primary care. A summary of these data is provided below.

For all skin tumours, the proportion biopsied in primary care ranged from 1.2% to 17%. Audit data estimated that:

- between 1.4% and 13% of MM are biopsied in primary care
- between 0.7% and 10% of SCC are biopsied in primary care
- between 1.3% and 8.8% of BCC are biopsied in primary care.

These proportions should reduce once this guidance is implemented.

A. Recommendations

It is recommended that the Royal College of Pathologists minimum dataset [30] is implemented in order to enhance the quality of cancer registration.

It is recommended that at least two cancer registries should receive additional funding to undertake full registration of skin cancers, including the registration of BCCs. Ideally this should include the registries covering the areas with the highest and lowest incidence of skin cancer.

Commissioners should implement the recommendations on skin cancer prevention outlined in the Health Development Agency document titled *Cancer prevention: A resource to support local action in delivering The NHS Cancer Plan* [14].

B. Anticipated benefits

Improved data collection on skin cancer should produce accurate population-based information on cancer incidence, prevalence, service utilisation, mortality and survival rates. These data will enhance the understanding of the epidemiology of skin cancer and the ability to monitor the impact of interventions. Specific benefits are envisaged in the following areas:

- *Prevention.* Population-based incidence data are required to monitor the achievement of targets for preventing cancer. This monitoring will probably be required for the next 10–20 years to see whether the current trend can be reversed.
- *Early detection.* Population-based data are required to monitor the effectiveness of early detection and health promotion programmes.
- *Improving access to specialist care.* Population-based data are required to monitor intervals between referral and treatment of cancer patients.
- *Improving treatment.* Treatment patterns need to be monitored to audit adherence to guidelines, effectiveness of interventions and outcomes. Data from cancer registries can identify the scope for NHS intervention. Information systems will have to be developed to support this process, including a palliative care dataset.

- *Improving the experience of care.* Access to specialist palliative care and place of death should be monitored to ensure optimal access and choice of place of death for patients.

Implementation of the advice set out in the Health Development Agency document titled *Cancer prevention: A resource to support local action in delivering The NHS Cancer Plan* [14] should start to change attitudes and behaviour towards UV exposure and enhance earlier detection of skin cancers.

C. Resource implications

There will be resource implications for the networks from the recommendations concerning the implementation of the Royal College of Pathologists minimum data requirements. This will be considered in the 'Initial investigation, diagnosis, staging and management' chapter of the guidance.

Cancer registries do not currently have the resources to collect data on all skin cancers. Much of the data collection will be facilitated in the future by developments in electronic data transfer as a result of the National Programme for Information Technology in England [31] and *Informing Healthcare in Wales* [32]. This will take some time to be fully implemented. In order that two cancer registries may undertake full registration of all skin cancers, the costs are estimated to be between £35,638 and £54,842 for the first year, while staff are trained. The annual recurring costs would be the same; the variation is dependent upon exactly how many additional staff are required. This cost is likely to decrease as registries that are not currently fully automated become so.

D. Audit and research priorities

Commissioners should ask their local cancer registries to undertake a joint audit with local clinicians of the current extent and quality of skin cancer registration in order to gain a better understanding of the relevance of local statistics for service planning.

The impact on mortality and survival from skin cancer of implementing this guidance should be evaluated.

Further research on the epidemiology of skin cancer is urgently required to improve the targeting of preventive interventions.

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Introduction

The NHS plan for England¹ and the Welsh Assembly Government document *Improving health in Wales*² aim to ensure that patients and the public have a real say in how NHS services are planned and developed. The DH paper *Involving patients and the public in healthcare*³ and the Welsh Assembly Government document *Signposts: a practical guide to public and patient involvement in Wales*⁴ set out new patient and public involvement structures for how this should be achieved.

Diversity of needs

Over the past decade there has been increased recognition of the need to develop services for patients with cancer or precancerous lesions that are more sensitive to their needs. This has been evidenced by the patient focus in the series of *Improving outcomes in cancer*⁵ guidance for commissioners. Areas of service provision that have received particular attention include:

- provision of information
- patient involvement in decision-making about treatment
- provision of support services, including psychological support and services from allied health professionals (AHPs).

The NICE guidance on *Improving supportive and palliative care for adults with cancer*⁶ provides a wide-ranging evidence-based overview of the generic issues for cancer patients but does not specifically address those for skin cancer patients.

¹ Department of Health (2000) *The NHS plan*. Available from: www.dh.gov.uk

² National Assembly for Wales (2001) *Improving health in Wales*. Available from: www.wales.gov.uk

³ Department of Health (2001) *Involving patients and the public in healthcare*. Available from: www.dh.gov.uk

⁴ National Assembly for Wales/OPM (2001) *Signposts: a practical guide to public and patient involvement in Wales*. Available from: www.wales.gov.uk

⁵ www.doh.gov.uk

⁶ National Institute for Clinical Excellence (2004) *Improving supportive and palliative care for adults with cancer*. Available from: www.nice.org.uk

Skin cancer patients are a large group of patients with diverse needs according to:

- whether lesions are precancerous or cancerous
- histological type
- anatomical site
- difficulty in resection or treatment
- risk of disfigurement and stage at diagnosis.

The needs of skin cancer patients differ from those of patients with other cancer types. Most patients will not have life-threatening disease. For the majority of patients with skin cancer or a precancerous lesion, the risk of metastatic disease is low. With sufficient support, patients can play an active role in self-examination and surveillance and will not need to be followed up in hospital. Nevertheless, it should be recognised that in some patients there is a significant risk of developing metachronous (new primary) lesions.

Most patients with precancerous lesions and a significant number of patients with low-risk BCC can be safely managed in primary care according to the model proposed in this guidance. This will require consideration of patient choice and provision of information to patients as well as access to a specialist nurse and other supportive services that are traditionally only available in hospitals.

Only a small proportion of skin cancer patients require specialist palliative care. It is particularly important to ensure that these patients do not slip through the net of referral by ensuring that all patients with advanced disease are discussed at the SSMDT meeting (see chapter on ‘Organisation of skin cancer services’).

Cancer waiting time targets

The current national cancer waiting time targets in England and Wales apply to MM and SCC but exclude BCC, Bowen’s intraepidermal SCC and other precancerous skin lesions. In England the target for patients with MM and SCC referred through the 2-week urgent GP referral route is that they must start their first definitive treatment within 62 days of GP referral.^{7,8} For all other patients with SCC and MM in England the target is that they must start their first definitive treatment within 31 days of the decision to treat.

⁷ Department of Health (2002) *The NHS cancer plan*. Available from: www.dh.gov.uk

⁸ Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk

This document and the NICE *Referral guidelines for suspected cancer*⁹ provide consistent guidance on how patients suspected of having a skin cancer should be referred urgently through the 2-week GP referral route.

In Wales patients referred via the 2-week urgent GP referral route, and confirmed urgent by a member of the MDT, must start their definitive treatment within 6 weeks of receipt of referral for MM and within 2 months of receipt of referral for SCC.¹⁰ Patients with BCC should be seen by the relevant specialist within 2 months of receipt of referral by their GP and be subsequently treated within a further 3 months.

Specific groups

A small proportion of skin cancer patients will require treatment that may result in disfigurement, particularly on the face, head and neck. Psychological support is essential, both before and after the disfiguring treatment, to enable patients to adjust psychologically and socially to their disfigurement and to develop coping strategies. A small proportion of patients who have more severe problems may need, and should have access to, psychiatric assessment and treatment via a liaison psychiatry service. Patients also need access to prosthetic, camouflage and lymphoedema services.

Specific needs arise for children and young people who develop ‘adult-type’ skin cancers, for patients with genetic disorders predisposing them to skin cancer, and for organ transplant patients. These are addressed in the chapter on ‘Management of special groups’.

Carers have a key role in supporting patients and may need information to enable them to fulfil this role optimally. However, patient-specific information should only be provided to carers within the context of protecting patient confidentiality and with the patient’s consent.

⁹ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

¹⁰ Welsh Assembly Government (2005) *National Standards for Skin Cancer Services*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

A. Recommendations

Putting patient and carer needs at the centre of service design

Cancer networks, through their site-specific groups and lead commissioners, should describe the demographic profile of the skin cancer patients in their area in order to ensure that their needs are adequately met. In particular they should consider the impact of affluence and poverty on stage at presentation and ensure access to the entire range of services from prevention through to palliation.

Commissioners should develop an understanding of the spectrum of needs of service users through consultation arrangements and ensure that individuals from the local community have the facility and the confidence to raise and express concerns.

Commissioners, together with their cancer network site-specific groups, should take into consideration the diversity of patients' needs when configuring services and developing network protocols.

Communication, information provision and support

Those who are directly involved in treating patients should receive specific training in communication and breaking bad news. They have a responsibility for good communication with patients and carers, including discussion of the risks and benefits in deciding about treatment options and involving patients as partners in care and treatment.

Each LSMDT and SSMDT should have at least one skin cancer clinical nurse specialist (CNS) who will play a leading role in supporting patients and carers. There should be equity of access to information and support regardless of where the care is delivered.

All LSMDTs and SSMDTs should have access to psychological support services for skin cancer patients.

Patients should be invited to bring a companion with them to consultations.

A checklist may be used by healthcare professionals to remind them to give patients and carers the information they need in an appropriate format for prediagnosis, diagnosis, treatment, follow-up or palliative care. This may also include a copy of the letter confirming the diagnosis and treatment plan sent by the consultant to the GP. In addition, there should be an assessment at these key stages to ensure that all other needs are met (for example, rehabilitation, psychological needs and occupational therapy).

Improved, preferably nationally standardised, written information should be made available to all patients. Information should be appropriate to the patients' needs at that point in their diagnosis and treatment, and should be repeated over time. The information given must be specific to the histopathological type of lesion, type of treatment, local services and any choice within them, and should cover both physical and psychosocial issues. The information should detail local services, including names of key personnel and contact details. The information given should be recorded in the patient notes. It is envisaged that much of this communication will be undertaken by skin cancer CNSs.

As there is a significant risk of developing further disease (that is, those patients who have had one type of skin cancer may develop a new and different lesion), all patients with cancerous or precancerous lesions should be given advice on prevention and recognition of signs and symptoms of suspicious skin lesions and on how to re-access the service. This may need to be an iterative process.

Information could be provided in the form of a hand-held record, containing information leaflets appropriate to the patient's needs and including local information on access to services and information about relevant local and national support groups. This would be particularly useful for more aggressive tumours such as MM or invasive SCC, which require multidisciplinary team support. This can serve as a record of treatment, including the patients' experiences and questions they wish to raise with the clinical team.

Patients should also, if appropriate, be given other information to take home in the most suitable format, e.g. audiotapes of consultations, copies of letters between clinicians and the patient, video or specialised material for people with learning disabilities, with adjustments made for different sociocultural contexts.

When a diagnosis of MM or SCC is given, the patient's GP should be informed of this result within 24 hours of the patient being told, regardless of where the diagnosis took place.^{11,12} This should ensure that patients are provided with the appropriate information and support. Patients with a BCC or precancerous lesion are not covered by this standard, although it is desirable.

Support for patients needing extensive treatment

All patients with skin cancer, but especially those with MM and advanced disease or those undergoing potentially disfiguring surgery, should be assessed and have access to, as appropriate, psychosocial, psychological and psychiatric interventions. Research indicates that the severity of a disfigurement does not correlate with the amount of distress it causes. Therefore it is important that services are configured in such a way that people with minor disfigurements are also made aware of the support and interventions available. They should also have access to other suitably trained counsellors and specialist services as appropriate, including those who can teach coping skills, give camouflage advice, provide occupational therapy and help with any preparation necessary for reconstructive surgery.

Rarely, patients with skin cancer may also develop lymphoedema following their treatment, and should have access to lymphoedema services if necessary.

Skin cancer CNSs should receive training in identifying and responding to the needs of patients undergoing disfiguring treatment, particularly with respect to coping skills, and in the identification of the need for psychological/psychiatric support.

All cancer networks should ensure that skin cancer patients have access to palliative care advice and support when needed.

Research

All patients, including those younger than 19 years of age, should be given the opportunity, if appropriate, to take part in clinical trials.¹³

¹¹ Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk

¹² Welsh Assembly Government (2005) *National Standards for Skin Cancer Services*.

Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

¹³ Department of Health (2004) *National service framework for children, young people and maternity services*. Available from: www.dh.gov.uk

Quality assurance

Surveys of patients' experiences should be a routine part of the quality assurance process of skin cancer services. These should be combined with more specific audits of aspects of care that may directly impact on patients' well-being. The results of these should be reviewed as part of MDT working.

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

Patient-centred care

B. Anticipated benefits

Once commissioners have obtained a clear picture of the local skin cancer patient population (demographics and expressed needs), they will be in a better position to ensure that services are developed to meet their needs. It is particularly important that the potential effects of deprivation, ethnicity, gender and age on access to, or benefit from, local skin cancer services are understood, and any inequalities addressed.

The production of patient-focused network protocols will help to ensure that all patients receive appropriate care and support.

The benefit to patients of clinical staff undergoing training in communication skills, particularly in breaking bad news, is well recognised.

The benefit to patients of access to CNSs is well documented.

Skin cancer CNSs who have received training will be better equipped to identify and assist with the management of patients with psychosocial needs.

It has been widely shown in cancer care, and to a small extent for skin cancer patients, that coping strategies are better and psychological morbidity less where patients are given plenty of appropriate information in a variety of formats and also the opportunity to discuss their concerns. Similarly, it is widely accepted that it can be beneficial for patients to bring to the consultation carers who will help them remember information conveyed.

The use of prompts (checklists) provides a safeguard in that clinicians are less likely to forget to give appropriate information.

It is anticipated that advice on sun protection and early recognition of skin tumours will result in better outcomes for patients.

Communication of results to the patient's GP within 24 hours for MM or SCC and in a timely fashion for BCC or precancerous lesions will enable him or her to provide better support to the patient.

A higher level of entry into clinical trials will help to produce the evidence base to underpin treatment decisions. Currently some patients are frustrated that they are not offered these opportunities.

Patients undergoing extensive and/or disfiguring treatment are more likely to have reduced psychological morbidity and to achieve better adjustment if they are given access to psychological/counselling support before and after the treatment and have serious psychiatric morbidity recognised early and treated.

As the need for supportive and palliative care is often mistakenly perceived to be less common in skin cancer patients, it is important that those who require it are not left unrecognised. Therefore consideration should be included in local and network-wide protocols.

The regular use of surveys of patients' experiences combined with more detailed audits, reviewed at MDT meetings, will enable areas for improvement and successes to be identified.

C. Evidence

Existing guidance

NICE has issued guidance on *Improving supportive and palliative care for adults with cancer* and *Improving outcomes in children and young people with cancer*. However, patients with skin cancer have specific needs that are not explicitly addressed. Furthermore, the supportive and palliative care guidance applies to adults with cancer, whereas this guidance is intended for all patients with skin cancer, including children and young people.

Patients' experiences and needs

There is evidence from observational studies that patients with skin cancer experience considerable distress at different stages of illness, including the time of diagnosis, and also during palliative treatment.

One cross-sectional study found that patients who are recently diagnosed with MM need information about the diagnosis and treatment, life expectancy and the likely effect on work and family life. A focus group study found that patients have difficulty in absorbing information at the time of diagnosis.

One observational study estimated that the majority of psychiatric morbidity experienced by patients with cancer goes unrecognised and therefore untreated.

The patient survey commissioned for this guidance found that while a majority of patients with skin cancer reported that they did not have special needs during their treatment, a majority also thought that skin cancer had affected their life, most commonly in terms of sun awareness.

Provision of information to cancer patients

One randomised controlled trial (RCT) found that in patients with melanoma, an intervention group randomised to receive a 1.5-hour, nurse-led teaching session with provision of an educational brochure had greater satisfaction with their information, a higher level of knowledge of melanoma and a lower proportion of patients requesting further information, compared to the control group. No differences in psychological and psychosomatic variables were found between groups.

One RCT provided cancer patients receiving an initial diagnosis or worsening prognosis with an audiotape of the consultation. Patients with the audiotape rated it positively and recalled more information about their illness than control patients, but there was no difference in psychological improvement between groups.

One RCT found that providing outpatients with a prompt card of questions to ask during their consultation did not influence whether patients asked questions, although many patients found the prompt card helpful. The authors concluded that patients also need encouragement from staff to ask questions.

One systematic review found that provision of communication skills training for health professionals in cancer care improves their skill in using focused and open questions, controlling follow-up interviews and using emotional speech.

One systematic review found that interventions which provided information to patients with cancer improved patient outcomes, including affective state, knowledge, understanding and satisfaction. Provision of preparatory written information before patients attended a first consultation was also shown to be beneficial.

One systematic review found that the majority of patients with cancer considered audiotape recordings or summaries of their consultations valuable. Recordings or summaries were associated with better recall of information and greater patient satisfaction with the information. No studies detected any statistically significant effect on anxiety or depression.

One systematic review of studies of communication in general healthcare settings found significant associations between communication interventions and patient health outcomes. Patient education was found to influence both emotional and physiological status, while physician education was found to influence emotional status.

Disfigurement

One RCT found that the factors related to a negative cosmetic impact were severity of scar and the extent to which patients were unprepared for the actual size of their scars. Provision of photographs as a means of preparing patients for cosmetic impact of surgery did not increase the accuracy of patients' expectations of their postoperative appearance and had no effect on levels of preoperative or postoperative distress.

One non-randomised intervention study found that a social interaction skills workshop for people with disfigurement was associated with reduced scores on scales of anxiety and social avoidance at both 6 weeks and 6 months follow-up.

One non-randomised intervention study found that nurses working in specialist units were less prepared to assist in social rehabilitation for patients with disfigurement than in physical rehabilitation. Self-perceived social rehabilitation skills improved significantly following a training programme.

Service guidelines produced by the British Association of Plastic Surgeons and the NHS Modernisation Agency (2005) are supportive of a patient-focused, rather than specialty-focused, model of care for patients treated with plastic surgery. The guidelines recommend that patients should be partners in their own management and also that carers should receive support.

Effectiveness of psychological interventions

One RCT found that a cognitive-behavioural intervention was not associated with significantly lower distress in patients with melanoma at the 2 months and 6 months follow-up points, although effects were noted on anxiety and health-related quality of life.

One RCT conducted with patients with melanoma found that a 6-week structured psychiatric group intervention improved patients' affective states and coping styles at 6 weeks follow-up and at 6 months follow-up.

One RCT conducted with patients with melanoma found that a 6-week, structured psychiatric group intervention, which included health education, was associated with a survival advantage, after adjusting for gender and Breslow thickness.

Evidence from systematic reviews and meta-analyses suggests that psychological, educational and supportive interventions are beneficial for patients with cancer.

Effectiveness of patient feedback

Evidence from an observational study suggests that patients with cancer who respond to questionnaire surveys are younger and experience fewer illness-related problems than patients who do not respond. Two expert reviews reported that rigorously designed patient-satisfaction questionnaires can bring about improvement in service provision, in terms of better implementation of guidelines, improvement of safety and increased patient satisfaction.

Clinical trials

One high-quality systematic review investigated patient outcomes related to mortality and morbidity among participants and non-participants in clinical trials. RCTs of different specialities were included, but the largest proportion was of patients with cancer. The review found little evidence for better outcomes through participation in trials aside from those arising from the effects of the treatments compared, or differences between participants and non-participants. The same review found no evidence of greater risk arising from trial participation.

A previous, poorer-quality systematic review than the one cited above examined evidence for better patient outcomes through RCT participation. The majority of RCTs were of patients with cancer. The review concluded that it is likely that clinical trials have a positive, rather than a negative, effect on survival and morbidity outcomes, with benefits arising from the use of trial protocols.

One literature review found that children and adolescents with melanoma are not entered into clinical trials. Retrospective studies have found that adolescents with cancer are not as likely to be entered into clinical trials as children and adults.

An audit of skin cancer MDT activity undertaken in the South West of England found that many trusts did not have sufficient infrastructure to ensure that patients are offered trial entry.

An audit of implementation of recommendations made in the Calman–Hine Report (1995) undertaken by the Commission for Health Improvement (CHI) and the Audit Commission in 2001 found that only a small proportion of patients with cancer are involved in clinical trials. Trial participation was less likely in settings outside of large cancer centres.

Improvement of services

The patient survey commissioned for this guidance found that patients expressed a perceived need for service improvement. Respondents wanted shorter waiting times, more accessible information about skin cancer, better education of GPs in the recognition of skin cancer and better communication by clinical staff. One-third of respondents had experienced delays in diagnosis, which was attributed by patients to failure of their GP to recognise the seriousness of the condition.

One systematic review found that, in the treatment of patients with advanced cancer, specialist palliative care teams result in better outcomes than conventional care, in terms of patient satisfaction and reduced hospital stays for patients in acute settings.

One expert review reported potential benefits of protocol-based care, including reduced length of hospital stay, reduced cost, improved patient quality of life, satisfaction with service and greater patient or carer participation in care.

D. Measurement

Structure

- Skin cancer teams working to network-agreed, patient-focused protocols that incorporate sections on communication, patient choice and monitoring patient satisfaction.
- The availability of a wide range of information in different formats.
- At least one skin cancer CNS in every skin cancer MDT (see chapter on ‘Organisation of skin cancer services’).

- Every skin cancer MDT having access to evidence-based psychosocial, psychiatric and psychological support and interventions, particularly for skin cancer patients with disfigurement.

Process

- Surveys of patient satisfaction covering, over time, all aspects of patient experiences.
- Documentation of information given and recorded in the case note and hand-held record of information given to the patient (where appropriate).
- Evidence that patients have been given written information describing the procedures they undergo, and that this information covers the resultant risks as well as anticipated benefits.
- Evidence that patients are being offered entry into clinical trials where appropriate.
- Evidence that the psychosocial needs of patients are considered at MDT meetings.
- Referral rates to psychosocial support services and other support services such as camouflage.

Outcome

- Evidence of patient and public involvement in strategy development.
- Evidence of lower levels of psychological morbidity.
- Patient satisfaction with services.
- Receipt of diagnosis by the patients' GP of MM and SCC (and ideally BCC) within the recommended timeframe of 24 hours.^{14,15}
- At least the minimum level of entry of appropriate patients into clinical trials as recommended by the National Cancer Research Network (NCRN) and Wales Cancer Trials Network (WCTN).^{16,17}

¹⁴ Department of Health (2002) *The NHS cancer plan*. Available from: www.dh.gov.uk

¹⁵ Welsh Assembly Government (2005) *National Standards for Skin Cancer Services 2005*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

¹⁶ Welsh Assembly Government (2005) *National Standards for Skin Cancer Services 2005*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

¹⁷ www.ncrn.org.uk

E. Resource implications

Putting patient and carer needs at the centre of service design

There will be resource implications associated with the introduction of consultation arrangements to develop an understanding of service users' needs. This cost has not been included in the economic review.

Communication, information provision and support

The main resource implication of the recommendations in this section will primarily be in increased numbers of skin cancer clinical nurse specialists (CNS). Skin cancer CNSs will have an increasing role to play in skin cancer patient care as a result of the guidance. The economic implications of this will be considered in the 'Organisation of skin cancer services' chapter.

It is anticipated that a further four or five skin cancer CNSs per network would be needed to ensure that each LSMDT and SSMDT has at least one skin cancer CNS. This estimate does not include provision for community-level care. The annual employment cost of a skin CNS is estimated to be £35,580 including oncosts. The additional salary cost per network would be between £142,330 and £177,913. This would not necessarily be all new money.

Support for patients needing extensive treatment

There will be resource implications as a result of skin cancer patients having access to both psychosocial and psychological interventions to help them come to terms with the result of surgery. The CNS will have a significant role here. The cost implications of increased provision of skin CNS has been included in the 'Organisation of skin cancer services' chapter.

Camouflage advice to skin cancer patients is often provided with the assistance of voluntary agencies. The British Red Cross provides a skin camouflage service throughout the UK to patients who require it, not just those with skin cancer. The British Red Cross trains volunteers to provide skin camouflage for 6500 people per year; annual training costs for the volunteers are at least £30,000 (accounting year 2003/04). This is inclusive of training costs, travel and provision of an equipment kit for each volunteer. Thirty volunteers are trained per year. There are currently 240 active volunteers working in 200 placements, mainly hospital dermatology departments and Red Cross branches. The Red Cross Camouflage Service has a patient-centred approach and therefore it is not possible

to estimate a separate cost for services for skin cancer patients. There is no charge for this service, to the patient or the NHS, although some patients make a donation. Training for nurses in skin camouflage techniques is in addition offered by the British Association of Skin Camouflage, also a voluntary agency.

Commissioners should take into consideration this significant contribution from the voluntary sector; if this funding ceases to be available, commissioners will need to find the requisite resources.

Research

The resource implications of the research recommendation have not been formally costed; it is likely to have cost implications for the research funding agencies.

Quality assurance

No formal estimate has been made of the resource implications of introducing patient surveys as a routine part of the quality assurance process of skin cancer services. However, no major resource implications are anticipated.

F. Audit and research priorities

Audit priorities include:

- access to information sources and information about the quality of patients' experiences
- access to appropriate supportive care for patients undergoing disfiguring treatment
- offer of entry into clinical trials for appropriate patients.

In terms of research, there is an urgent need for larger studies on the experiences of patients with precancerous lesions and skin cancer. In particular there is a need to look at the impact on quality of life of living with surveillance for future cancers. Studies are also needed to determine the benefit of self- or clinician-conducted surveillance. There is a need to gain a better understanding of the needs of patients with advanced disease and/or those requiring major and/or disfiguring treatment. Research should also be undertaken to assess the impact of interventions to reduce psychological morbidity and to improve psychosocial well-being.

Organisation of skin cancer services

3

Introduction

Currently there are large variations in the way in which skin cancer patients are seen and treated. Evidence from local audits shows that in some areas significant numbers of patients with precancerous skin lesions and BCCs, and smaller numbers of patients with SCC and MM, are managed entirely in primary care, often with no contact with the local hospital MDT and no audit of their outcomes. The recommendations in this guidance should help ensure that all patients in England and Wales who have any type of skin cancer are treated to the same standards and that the treatment outcomes are audited.

Diagnosing and recommending appropriate management for skin lesions requires specialist skills as emphasised by the NHS Modernisation Agency.¹⁸ This is important to ensure timely management of skin cancer and the avoidance of unnecessary skin surgery. The NHS Modernisation Agency specifically recommends that ‘The diagnostic and management phases of the treatment of skin lesions should ideally be considered separately.’ In the light of this, this guidance proposes that the diagnosis and treatment planning of all suspicious pigmented lesions, all skin lesions that may be MM, SCC or high risk BCCs, and any other skin lesion that may be a skin cancer but where the diagnosis is unclear, should be carried out only by specialists (normally dermatologists) who are suitably trained and who are part of the hospital MDT network (see section on ‘Cancer networks’).

Different degrees of specialisation are required to treat the various types and stages of skin cancer. Unlike other cancers, the majority of precancerous lesions and BCCs carry no risk of death and have a low risk of recurrence. The treatment and follow-up of patients with these lesions may be carried out by trained doctors and nurses with relatively straightforward outpatient or day care. Such care may be provided in a community setting by appropriately trained doctors and specialist nurses working within a formal, audited and professionally led framework. Patients with lesions that are more difficult to treat may have their treatment carried out within the local dermatology

¹⁸ NHS Modernisation Agency. *Action on plastic surgery programme*. Available from: www.modern.nhs.uk

department or they may be referred to a variety of other specialists appropriate for their needs. Although few patients with MM and SCC are currently treated in the community (1.4–13% for MM and 0.7–10% for SCC), delay, misdiagnosis or mismanagement could have a serious effect on their chances of survival (see Evidence Review). Therefore these patients need to be managed by a hospital-based MDT.

Precancerous lesions of the skin are common. Prevalence studies have demonstrated that approximately 23% of the population aged 60 years and older have actinic keratosis (AK). Most patients with precancerous skin lesions can be managed by their GP or by a clinician working in the community (see ‘Clinicians working in the community’). However, where there is doubt about the diagnosis the patient should be referred to the hospital dermatology department.

Some treatments for well-defined groups of patients may be carried out in the community by a variety of clinicians, including GPs with a special interest (GPwSI) in skin cancer. A recent audit of GPwSIs in dermatology has shown that many PCTs/LHBs are not following the guidelines for GPwSI working agreed and published by the Royal College of General Practitioners (RCGP), BAD and DH.^{19,20} It is essential that these guidelines are adhered to by GPwSIs who wish to see and treat patients with skin cancer, in order to ensure a high quality of care for these patients.

This guidance is proposing a structured approach to the organisation of the management of patients with skin cancers, with firm recommendations on which types of skin lesions can be diagnosed and treated in the community, local hospitals and specialist centres. The proposed structure should standardise care regardless of where the patient is treated and should minimise the risks to patients, because all clinicians who treat patients with skin cancers will be working to the same protocols and have their outcomes audited. It will encourage some treatments for patients with precancerous skin lesions and low-risk BCCs to be carried out in the community but ensure that patients with MM, SCC and high-risk BCC have their care managed by a hospital-based MDT with specialist skills.

¹⁹ British Association of Dermatology (2002) *Service provision guidelines: GPs with a special interest in dermatology*. British Association of Dermatologists’ position statement. Available from: www.bad.org.uk/healthcare/service/statement.asp

²⁰ Department of Health (2003) *Guidelines for the appointment of GPs with special interests in the delivery of clinical services: dermatology*. Available from: www.dh.gov.uk

A. Recommendations

Cancer networks

All patients with skin cancer, and their carers, should be offered the same quality of treatment, information and support regardless of where the diagnosis is made and treatment is carried out, and regardless of the grade or type of doctor they see.

All doctors and nurses knowingly treating patients with skin cancer should be members of one of the MDTs described in this section.

All cancer networks should, through their skin cancer site-specific network group, establish two levels of MDT for the management of patients with skin cancer, both of which will also provide MDT support for clinicians working in the community:

- local hospital skin cancer multidisciplinary teams (LSMDTs)
- specialist skin cancer multidisciplinary teams (SSMDTs).

Commissioners should ensure that adequate resources are made available in order that skin cancer teams can work in accordance with this guidance, and have staff to undertake prospective data collection and audit.

All hospital doctors who treat patients with skin cancer should be active members of a skin cancer MDT and attend more than 50% of the total meetings annually.

Doctors who knowingly treat skin cancer patients in the community should be members of an LSMDT/SSMDT. As they will be treating only those patients with low-risk BCC and precancerous skin lesions (see section on ‘Clinicians working in the community’), they will not have the same requirement for attendance at an MDT as other members, but would be expected to attend at least four meetings a year, one of which should be an audit meeting. They would also be expected to attend if one of their patients is to be discussed.

For consultants, the clinical and managerial work related to skin cancer service delivery should be incorporated into their job plans.

The 2-week waiting time standard and other national waiting time standards should apply in every setting within the system where care is delivered, and not only to hospital-based care (see definitions in chapter on 'Patient-centred care').

Network implementation

Substantial changes in working practices and new resources may be required to create the service described in this guidance. Each cancer network should undertake an audit/appraisal of the quality of their current service provision and then decide how to establish the teams, which are central to the recommendations.

Network-wide protocols

Documented clinical protocols for referral and treatment should be agreed between the lead clinician of the LSMDT and SSMDT, ratified by the skin cancer site-specific network group and signed off by the lead clinician of the cancer network. Effective systems will be required to ensure rapid communication and efficient coordination between teams. This guidance and other national clinical guidelines should be used in the development of local protocols and guidelines at the cancer network level.

Arrangements for skin cancer teams

LSMDTs should be established in cancer units at district general hospitals and link with all those engaged in skin cancer care in the community and primary care.

SSMDTs should be based in larger hospitals, usually cancer centres, plastic surgery centres or other specialist tertiary services of relevance to skin cancer. These teams can also serve as the LSMDT for the local population. The teams should include appropriate non-surgical oncology support.

Patients should be referred for review from LSMDT to SSMDT according to the complexity of their disease (see Table 4). There should be flexibility in these arrangements to allow for local circumstances, including the management, by other specialist cancer MDTs, of patients with skin cancers of either specific types or specific anatomical location. Where this occurs, the cases need only be included in the discussion at one MDT but data on all skin cancers should be brought together in a single audit. For some rare skin cancers and sites, such as vulval melanoma, it may be appropriate that more than one MDT is involved in the treatment decisions.

Coordination across teams

It is important that the transfer of care of patients between teams is as flexible, comprehensive and timely as possible to avoid undue delays and ensure continuity of care. Close coordination is required between clinicians working in the community, LSMDTs, SSMDTs, palliative care teams and patients, carers and their families. There should be a designated individual in each team who has responsibility for communication and information provision, and adequate support must also be provided to ensure that all discussions about patient management are recorded.

Clearly defined arrangements should be made to ensure that appropriate information (including the name of the doctor and CNS who are directly responsible for each patient) is communicated properly to each patient and others (such as GPs) who may require, or may benefit from, information about decisions concerning particular patients. GPs should be given sufficient information about each patient's cancer and his or her management to enable them to advise and support patients and their carers.

There should be clear and documented arrangements for cross-cover in all teams and all members should meet the MDT attendance criterion. This commitment should be formally acknowledged in the consultant contract as programmed activity (PA).

It is recognised that a period of transition will be required before the new pattern of service provision is established.

Patient information

Trusts should provide information to patients, as outlined in the chapter on 'Patient-centred care'. If patient support groups or user involvement groups exist, then information on these should also be provided for patients. Information should contain details of the patient's specific condition and treatment, relevant MDTs, contact names and phone numbers, clinical appointments and a diary in which patients can record symptoms and other potentially useful information about their condition if appropriate. This will be of value both for the patient's own use and to other healthcare professionals required to care for the patient out of normal working hours.

The local hospital skin cancer multidisciplinary team (LSMDT)

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

*Organisation of skin
cancer services*

The LSMDTs should serve populations in excess of 200,000. Core teams should include, at a minimum, the members specified in this section. All members of each team should have a particular interest in skin cancer and these designated individuals should provide treatment. Review at an MDT meeting is only necessary for those patients to whose management it may make a difference. This may be when there are treatment choices, when management is challenging and would benefit from the input of several professionals, or when the diagnosis is difficult. The cases for LSMDT review are listed in Table 2.

Table 2. Patients to be referred for LSMDT review

- All patients with SCCs or high-risk BCCs that involve the excision margins or are recurrent
- All patients with MM – primary, recurrent and metastatic
- Patients suitable for Mohs surgery
- Patients with skin lesions of uncertain but possible malignant nature
- Cases for nodal dissection including sentinel node biopsy (SNB)
- Immunocompromised patients with skin cancers and patients who have Gorlin's syndrome or other genetic conditions in which predisposition occurs
- Patients with rare skin cancers (see Appendix 1) including lymphoma
- Patients for whom there is a discrepancy between the clinical diagnosis and histopathology report

3

The role of the LSMDT

The LSMDT should:

- Provide a rapid diagnostic and treatment service, ideally in the same clinical session.
- Identify and manage all patients with skin cancer in secondary care except those who require referral to the SSMDT (Table 4).

- Be responsible for the provision of information, advice and support for all patients and their carers throughout the course of the illness; this should include those who are receiving most of their care from doctors outside the MDT, e.g. physicians caring for the elderly.
- Provide treatment and follow-up for patients and ensure that every patient with invasive skin cancer is documented (discussed or audited) by the MDT.
- Audit the management of all patients with excised BCCs and SCCs not discussed at MDT meetings. This audit should be presented to the MDT on a quarterly basis.
- Provide a rapid referral service to the SSMDT for patients who require specialist management (see Table 4).
- Ensure that GPs are given prompt^{21,22} and full information about any changes in their patients' illness or treatment.
- Refer cases requiring a second histological opinion to the lead histopathologist in the SSMDT.
- Ensure that all eligible patients are entered into approved clinical trials. If the trial is coordinated through the SSMDT then all patients (regardless of stage) who are eligible should be referred to the SSMDT.
- Collect data for network-wide audit (Table 3).

Cases to be discussed at LSMDTs are summarised in Table 2. LSMDTs will concurrently refer certain patients on to the SSMDT (see Table 4).

Any patients who are recognised (clinically or histologically) to have skin cancers with the characteristics listed in Table 4 should be referred directly to the SSMDT.

In some cases, direct referral from the community to the SSMDT may be appropriate, for example in the rare situation where a GP finds that he or she has excised an MM. However, there may be benefits to a patient in being referred simultaneously to both LSMDT and SSMDT and meeting a member of the LSMDT early, because follow-up may take place there at a later date.

²¹ Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk

²² Welsh Assembly Government (2005) *National Standards for Skin Cancer Services*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

A function of the LSMDT is to audit management and in particular to ensure that wider/re-excisions have been adequately performed. As with BCC/SCC audits, this should be presented quarterly to the MDT. The LSMDT should also receive quarterly audit data from any clinicians working in the community (Table 3).

Core membership of the LSMDT

The LSMDT should include the following.

- *Designated lead clinician.* A designated lead clinician (normally a consultant dermatologist) who will take overall responsibility for the service.
- *Dermatologists.* There should be a designated lead and ideally a deputy lead, both with a special interest in skin cancer, and any dermatologist involved in skin cancer care should attend the MDT meeting.
- *Skin cancer clinical nurse specialists (CNS)* (as defined by the *Manual of Cancer Services*²³). Patient advocacy and provision of information and support for patients and carers are crucial aspects of this role. The CNS will play a key role in communication between the patients and the different specialties involved in management and must have a high level of communication skills. She or he should be able to provide practical support such as advice postoperatively. The CNS will also have an important role in the identification of patients' psychosocial needs and will advise on appropriate referral. The CNS may, if suitably trained, carry out a range of related service activities such as minor surgery, skin cancer surveillance and follow-up clinics in parallel with an appropriately trained doctor.
- *Histopathologists.* Histopathologists should take a lead role in skin cancer. Pathology reports should include all the information required by the current Royal College of Pathologists minimum dataset for the relevant cancer.²⁴ The histopathologists engaged in skin cancer diagnosis should participate in an appropriate external quality assessment (EQA) scheme and demonstrate evidence of continuing professional development (CPD) relevant to skin cancer. The lead histopathologist should attend over 50% of MDT meetings. Other histopathologists reporting skin cancer should be able to demonstrate some MDT activity.

²³ Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk

²⁴ Royal College of Pathologists. *Standards and datasets for reporting cancers*. Available from: www.rcpath.org

- *GPwSIs, trust clinical assistants and associate specialists.* Doctors regularly engaged in seeing skin cancer patients or undertaking skin cancer surgery should be encouraged to attend the skin cancer MDT as part of their contracted activities, and this should be recognised where appropriate for continuing medical education (CME). Their attendance should be a minimum of four times a year, which should include one audit meeting where patients with skin cancer who are not formally reviewed at MDT meetings are discussed.
- *Surgeons.* Surgeons who regularly perform excisional surgery should attend the MDT meeting and be designated within the trust as having a specialist interest in skin cancer.
- *Oncologists.* Not every LSMDT will have a clinical or medical oncologist available, but if local circumstances allow they should be part of the LSMDT.
- *Team coordinator/secretary.* A team coordinator/secretary should be appointed who will provide clerical support for the MDT. All decisions made by the team should be recorded and appropriate information properly communicated to those that require it. The attendance of all members of the MDT should also be recorded.
- For each of the specialties described above there should be a nominated lead and deputy.

Members of the extended LSMDT

The LSMDT should maintain close contact with all other professionals who are actively involved in treating and supporting patients. The extended team may include:

- specialists in palliative care
- trained counsellors with experience in cancer
- psychologists
- cosmetic camouflage advisers
- clinical geneticist/genetics counsellor
- occupational therapists
- prosthetics and orthotics staff
- physiotherapists

- lymphoedema therapists
- pharmacists.

Table 3. Example of activities in a rolling programme of audit

- Audit of all skin cancers to be presented annually, including those not discussed at the MDT
- Audit of all skin cancer excision margins according to published guidelines
- Waiting times according to national targets (see section on ‘Cancer waiting times targets’)
- Proportion of cases actually reviewed by the MDT according to criteria listed
- Critical incidents where treatments were judged to be outside recommended network guidelines – network meetings should take place annually to review such incidents
- Audit of histopathology reporting times
- Audit of Mohs surgery activity
- Audit of clinical trial entry

The specialist skin cancer multidisciplinary team (SSMDT)

Patients with invasive skin cancer associated with a greater risk or rarity should be managed by SSMDTs. These teams should be established in larger hospitals, usually cancer centres, plastic surgery centres or other specialist tertiary services of relevance to skin cancer and should provide a service for a minimum population of 750,000. These teams can also serve as the LSMDT for the local population. The teams should include appropriate non-surgical oncology support.

Specific cases for referral to the SSMDT are set out in Table 4. Where patients meeting criteria for SSMDT are identified by dermatologists that attend LSMDTs, review at the LSMDT may take place on the basis that referral to the SSMDT is immediate and should not be dependent upon the LSMDT review.

If two or more SSMDTs are established in one cancer network, there should be strong links between them. These SSMDTs should establish common clinical protocols across the network as a whole, and for the audit of all aspects of their work. Each team should appoint a lead clinician who will take an active role in the coordination of skin cancer services provided by the network as a whole.

If patients attend the SSMDT they should be seen in a combined or parallel clinic staffed by the core members of the SSMDT (see 'The role of the SSMDT'). The history, histology and radiology of those patients who attend the SSMDT should also be presented at the review meeting.

Patients with lymphoma and other rare skin cancers (see chapter on 'Management of special groups') should be dealt with by only one SSMDT in the network. All cases should be reviewed by the dermatopathologist designated by the network to have an interest in, and lead responsibility for, cutaneous lymphoma reporting. It is appropriate for the network lead dermatopathologist in lymphoma reporting to attend the clinics as necessary. The lead dermatopathologist in lymphoma reporting is likely to be, but is not necessarily, the SSMDT lead dermatopathologist.

The NICE guidance on *Improving outcomes in haematological cancers*²⁵ permits considerable flexibility for the type and number of lymphoma/leukaemia MDTs. Multidisciplinary primary cutaneous lymphoma clinics have developed in several networks and have been highly successful. In particular this model facilitates patient examination and clinicopathological correlation, which is often essential for the accurate diagnosis of cutaneous lymphoma. These multidisciplinary clinics can be encouraged to continue and develop, depending on appropriate geography and case numbers. With appropriate core membership these could achieve MDT status, but should formally feed back summaries to the SSMDT.

The role of the SSMDT

The SSMDT will also act as the LSMDT for their local catchment population. They should, in addition, review other specific groups of patients (Table 4); these will be referred in from other LSMDTs according to network protocols.

²⁵ National Institute for Clinical Excellence (2003) *Improving outcomes in haematological cancers*. London: National Institute for Clinical Excellence. Available from: www.nice.org.uk

SSMDT meetings should be at least fortnightly. The key roles of the SSMDT over and above that of an LSMDT are to:

- Provide a rapid diagnostic and treatment service (ideally at the same clinical session) for patients referred from LSMDTs.
- Provide specialist investigations and treatments not available to LSMDTs.
- Undertake research including entering patients into NCRN- and WCTN-approved clinical trials. Wherever possible patients should be considered for clinical trials (e.g. adjuvant therapies or surgical treatments). Where trials are adopted for surgical procedures on lymph nodes, these patients should be referred and coordinated by the SSMDT.
- Collect data for network-wide audit (Table 3).
- Play a lead role in Mohs surgery activity within the cancer network.
- Play a lead role in training and teaching health professionals about skin cancer.

The SSMDT should have access to ITU or high-dependency facilities for major surgical cases (for example, widespread tumours affecting the head and neck). It should maintain close contact with other professionals who may be involved in supporting patients or carrying out the management strategy decided by the team, so that rapid access to their services can be provided when required.

All cases referred to the SSMDT should receive formal diagnostic histopathological review. There may be a few exceptions; for example, cases referred with extensive BCC for surgical reconstruction. All cases requiring a tertiary histopathological opinion should be supported by the SSMDT on a commissioning basis.

Patients reviewed by the SSMDT should be seen by and referred from the LSMDT in most instances, unless the SSMDT is also the LSMDT. However, in order to avoid undue delays some patients may be referred directly from doctors working in the community.

Table 4. Patients for review by SSMDTs

- Patients referred from the LSMDT
- Patients with high-risk SCCs (see ‘Glossary of terms’, Appendix 6) that pose difficulty in management
- Patients with MM managed by other site specialist teams (e.g. gynaecological, mucosal and head and neck (excluding ocular))
- Patients newly diagnosed with MM stage 2B or higher (American Joint Committee on Cancer (AJCC) staging system)²⁶
- Patients with MM stage 1 or above who are eligible for clinical trials that have been approved at cancer network level
- Patients with multiple MM
- Children younger than 19 years with MM
- Any patient with metastatic MM or SCC diagnosed at presentation or on follow-up
- Patients with giant congenital naevi where there is suspicion of malignant transformation
- Patients with BCCs that are metastatic
- Patients with malignant skin lesions of uncertain pathological diagnosis
- Patients with rare skin cancers, including lymphoma and sarcoma (see chapter on ‘Management of special groups’)
- For periodic review, patients developing skin cancers who are immunocompromised, have Gorlin’s syndrome or other genetic predisposition syndromes (see chapter on ‘Management of special groups’)
- Patients needing nodal dissection including sentinel lymph node biopsy (SNB) – these patients should be seen and referred by the LSMDT
- Patients who may benefit from radiotherapy, if not available at the LSMDT
- Patients who may be eligible for entry into clinical trials
- Patients who require adjuvant treatment (where this is shown to be beneficial)

²⁶ American Joint Committee on Cancer (1992) *Manual for staging of cancer*. Philadelphia: JB Lippincott.

As set out in the section on ‘Arrangements for skin cancer teams’, patients with skin cancer occurring on the head and neck may be managed locally by head and neck cancer specialist MDTs and centres. These patients may be reviewed as appropriate by the SSMDT. There should be clear management arrangements and links between the SSMDT and other cancer site-specific MDTs.

Core membership of the SSMDT

The SSMDT should include the following:

- *Dermatologists.* There should be at least two dermatologists, one of whom should have a major interest in skin cancer and/or skin cancer surgery; another should ideally have a major interest in cutaneous lymphoma. There should be a designated lead and ideally a deputy lead, and any dermatologist involved in skin cancer care should attend the MDT meeting.
- *Surgeons.* At least two surgeons should have a designated interest in skin cancer surgery and perform at least 15 block dissections each (groin or axilla) per year. Radical or conservative neck dissections (for cancer of the head and neck) should only be done by specialists regularly undertaking this procedure or who are members of the head and neck cancer MDT. A combination could include plastic surgeons, surgical oncologists, oral and maxillofacial surgeons, oculoplastic surgeons and ENT surgeons. It may be appropriate locally to include as extended team members oculoplastic surgeons and reconstructive hand surgeons. Oculoplastic surgeons have a specific and important role in the management of skin cancers arising around the eye.
- *Skin cancer CNSs* (as defined by the *Manual of Cancer Services*²⁷). Patient advocacy and provision of information and support for patients and carers are crucial aspects of this role. The CNS will play a key role in communication between the patients and the different specialties involved in management and must have a high level of communication skills. She or he should be able to provide practical support such as advice postoperatively. The CNS will also have an important role in the identification of patients’ psychosocial needs and will advise on appropriate referral. The CNS may, if suitably trained, carry out a range of related service activities such as minor surgery, skin cancer surveillance and follow-up clinics in parallel with an appropriately trained doctor.

²⁷ Department of Health (2004) *Manual of Cancer Services*. Available from: www.dh.gov.uk

- *Histopathologists.* Ideally there should be at least two specialist dermatopathologists or histopathologists with a special interest in dermatopathology. This is to provide flexibility and adequate cover during leave periods. There should be a designated lead in the area and ideally a deputy lead. The lead and deputy lead engaged in reviewing and reporting SSMDT skin cancer cases should each attend over 50% of SSMDTs. Other histopathologists reviewing and reporting SSMDT work should be able to demonstrate some MDT activity. All specialist histopathologists reviewing and reporting common and rare skin cancers should be able to demonstrate experience, competency and skills sufficient to fulfil the task, or undertake appropriate training to acquire the skills. The level of competence and skills for this activity is broadly that of the RCPATH Diploma in Dermatopathology and American Board Certification in Dermatopathology. These qualifications are not, however, regarded as mandatory. All specialist histopathologists engaged in this work should participate in some CPD relevant to common and rare skin cancers and participate in an appropriate EQA scheme. Ideally this should be a national specialist EQA scheme in dermatopathology, when available. Those reporting primary cutaneous lymphoma must participate in an EQA scheme including this group of diseases. It is also desirable that the CPD is facilitated by membership of appropriate national societies (such as the British Society for Dermatopathology and/or the UK Cutaneous Lymphoma Group). Each cancer or pathology network could hold a panel of histopathologists suitable for SSMDT participation based on these criteria.

Histopathologists restricting their activity in the SSMDT centre to work at the LSMDT level should be able to demonstrate the same activity as defined previously. It is acknowledged that because of workforce shortages in histopathology there could be an implementation delay of these goals in some centres.

- *Radiologists.* Cross-sectional imaging is important for staging new cases and managing advanced cases. Sessional time must be identified to allow the radiologists to prepare for and attend the MDT meeting.
- *Clinical oncologists.* A designated clinical oncologist should be identified as a member of the SSMDT and should be present in both the clinic and MDT review meeting.
- *Medical oncologist.* A designated medical oncologist should be identified as a member of the SSMDT and should be present in both the clinic and MDT review meeting.

- *Palliative care specialists.* Since the management of complex invasive skin cancers (particularly metastatic MM) is often palliative, a palliative care specialist (either a doctor or a nurse) should be included in the core team. Patients with specialist palliative care needs should also be referred to the appropriate community palliative care services.
- *Team coordinator/secretary.* A team coordinator/secretary should provide clerical support, record meetings and ensure that all documentation required to inform MDT discussion is available at each meeting.
- For each of the specialties described above there should be a nominated lead and deputy.

Members of the extended SSMDT

The core members and those in the list below form the extended multidisciplinary team that meets at least once a year to decide and discuss local issues of service delivery and quality. The trust cancer services managers should attend such meetings.

The extended SSMDT may include:

- trained counsellors with experience in cancer
- psychologists
- liaison psychiatrists
- pharmacists
- cosmetic camouflage service advisers
- clinical geneticist/genetic counsellors
- lymphoedema therapists
- occupational therapists
- prosthetics and orthotics staff
- physiotherapists
- radiographers
- speech and language therapists.

Commissioning arrangements should be made by the cancer network for the funding of histopathology reviews from the LSMDT to the SSMDT, and by the cancer network for funding supranetwork pathology referrals from the SSMDT for tertiary opinions in difficult diagnostic cases.

Organisation of LSMDT and SSMDT meetings

The core LSMDT and SSMDT should meet at least every 2 weeks. The MDT should assume responsibility for all cases of skin cancer referred to them. All team members should attend the majority of meetings and should participate in collaborative decision-making, although different criteria apply to GPwSIs. At least once a year the LSMDT and SSMDT extended teams should meet with their core teams to discuss team and organisational issues with a designated trust manager.

3

Decisions about management and standards for therapy should follow documented clinical protocols that have been agreed throughout the network. These protocols should be demonstrably evidence-based and should be produced jointly by members of all the teams in the network that deal with skin cancer. Patients who fit the criteria for inclusion should be asked if they would like to participate in NCRN- and WCTN- recommended clinical trials.

Medical photography has an important role in the recording of clinical images for skin lesions and should be used where appropriate to aid decision-making at MDT meetings.

One member of the LSMDT/SSMDT (usually the lead clinician) should take managerial responsibility for the service as a whole. Audit of process and outcomes, and actions arising from audit results, should be discussed in team meetings (Table 3). Data collection systems should be compatible across pathology departments and all skin cancer teams to facilitate network-wide audit.

Meetings should be arranged by the team secretary/coordinator, who should ensure that information necessary for effective team functioning is available at each meeting. This will include a list of patients to discuss and copies of their case notes, along with diagnostic staging and pathology information.

Preparation and attendance at meetings should be recognised as a clinical commitment, and time should be allocated accordingly and reflected in consultant job plans. Team members should be adequately prepared for each meeting, so that cases can be discussed without delay. The team should elect a lead clinician who takes managerial responsibility and represents the team on the skin cancer network site-specific group.

Videoconferencing and teleconferencing should be considered to facilitate the holding of MDT meetings, especially in geographically dispersed areas and where time is a severe constraint.

All new cases should be discussed as well as those that have subsequent events following initial assessment and treatment. Straightforward cases treated to agreed national and local protocols may need very little discussion, but should be included.

Audit, clinical trials and other issues of relevance to the network should also be discussed at MDT meetings.

Clinicians working in the community

As described in the Background chapter, precancerous lesions of the skin and skin cancers are extremely common. Therefore, all GPs will be expected to recognise and make management decisions on patients with these conditions on a regular basis. This guidance recommends that while precancerous lesions can be safely managed by any GP who has undergone appropriate training (as outlined in the NICE *Referral guidelines for suspected cancer*²⁸), the planned treatment of low-risk BCCs should be restricted to approved doctors working in the community, usually a GPwSI (as described in this section), or the LSMDT/SSMDT. All other skin cancers should be referred to the LSMDT in the first instance.

In some areas, there may be suitably trained doctors who work in specialist hospital departments and who wish to see and treat patients with precancerous skin lesions and low-risk BCCs in the community. The need for community skin cancer clinics will vary according to the expertise available and ease of access to local hospital departments – they may well be more appropriate in rural areas than in urban areas. All doctors and specialist nurses working in the community who knowingly treat skin cancer patients should be approved by, and be accountable to, the local LSMDT/SSMDT skin cancer lead clinician. They should work closely together to agreed local clinical protocols for referral, treatment and follow-up. These should be coherent with network-wide clinical protocols and signed off by the network site-specific lead for skin cancer.

²⁸ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

Depending on local circumstance, community skin cancer clinics could be based in GPs' surgeries, community hospitals or diagnostic and treatment centres where these exist. Patients could be referred to these clinics by local GPs or members of the LSMDT/SSMDT. For instance, when a diagnosis of low-risk BCC is made in a dermatology clinic, the patient may prefer the surgery to be carried out in the community if the specialist agrees this to be appropriate. Patients could be seen by these teams for treatment and follow-up when appropriate, according to agreed protocols and patient choice (see Box 1 and Figure 14 for details of the patient pathway for different types of skin lesions).

Any doctor or specialist nurse who wishes to treat patients with skin cancer should have specialist training in skin cancer work, be a member of the LSMDT and undergo ongoing education (see section on 'Structure and clinical governance'). In the absence of a national body to determine the surgical training within the remit of skin cancer, this should be determined by the network site-specific group for skin cancer and be consistent with the NICE *Referral guidelines for suspected cancer*.²⁹ All doctors participating in the MDT should have a letter of appointment from the MDT lead clinician. Ideally all doctors treating patients with skin cancer should have attended a recognised skin surgical course. They should also work at least one session per week as a clinical assistant, hospital practitioner, associate specialist or staff-grade doctor in the local hospital department. This should be in a parallel clinic with an appropriate hospital specialist, normally a dermatologist, who is a member of the LSMDT/SSMDT. This applies to GPwSIs as well, as specified in the joint recommendations by the DH, RCGP and BAD.^{30,31} This is considered essential to maintain skills and promote dialogue with the specialist.

²⁹ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

³⁰ Department of Health, Royal College of General Practitioners (2003) *Guidelines for the appointment of general practitioners with special interests in the delivery of clinical services: dermatology*. Available from: www.dh.gov.uk

³¹ British Association of Dermatologists (2002) *Service provision guidelines: GPs with a special interest in dermatology*. British Association of Dermatologists' position statement. Available from: www.bad.org.uk

A basic knowledge of skin cancer histopathology reporting and terminology is expected. Eligible doctors should either be GPwSIs employed by the PCT/LHB or non-career-grade doctors employed by the hospital trust. PCTs and LHBs should only accredit GPwSIs for skin cancer work if they comply completely with the DH, RCGP and BAD guidelines on GPwSI working.^{32,33} The recommendations include the need for the GPwSI to work at least one session per week in the special interest area. The majority of the practitioner's time should be spent as a GP, and this is usually considered to be at least three sessions per week.

Skin cancer CNSs should work alongside the doctors and carry out some forms of treatment such as cryotherapy, skin surgery and photodynamic therapy (PDT). They would also be involved in counselling, health promotion and follow-up of selected groups of patients where appropriately trained and would also ensure that the necessary liaison occurs between the hospital and community-based care. Any doctor, nurse or other practitioner who carries out surgical procedures on skin cancer patients should be appropriately trained and have his or her work audited and appraised.

The role of the doctor working in the community

The doctor working in the community should:

- Manage and follow up, when indicated, patients with low-risk BCCs and precancerous lesions in the community (see Box 1 and Figure 14) by working to agreed protocols as defined by the lead clinician of the LSMDT/SSMDT.
- Provide a rapid referral service for patients who require specialist management through the LSMDT or SSMDT.
- Be responsible for the provision of information, advice and support for patients managed in primary care and their carers.
- Maintain a register of all patients treated, whose care should be part of a regular audit presented to the LSMDT/SSMDT.
- Liaise and communicate with all members of the skin cancer site-specific network group.

³² Department of Health, Royal College of General Practitioners (2003) *Guidelines for the appointment of general practitioners with special interests in the delivery of clinical services: dermatology*. Available from: www.dh.gov.uk

³³ British Association of Dermatologists (2002) Service provision guidelines: *GPs with a special interest in dermatology*. British Association of Dermatologists' position statement. Available from: www.bad.org.uk

- Ensure that referring GPs are given prompt and full information about their patients' diagnosis or treatment in line with national standards on communication to GPs of cancer diagnoses.
- Collect data for network-wide audit.

Management of patients presenting in primary care

The NICE *Referral guidelines for suspected cancer*³⁴ recommendations for skin cancer should be followed. These primarily relate to referral to a specialist in secondary care from a non-specialist GP.

Clinical guidelines have been published by the BAD and NICE for management of NMSC and by the BAD, British Association of Plastic Surgeons, Melanoma Study Group and NICE for the management of MM.^{35,36,37,38} The recommendations for management of specific tumour types in primary care are summarised in Figure 14 in the 'Initial investigation, diagnosis, staging and management' chapter and are consistent with these clinical guidelines. These clinical guidelines have also been included within the Evidence Review.

Structure and clinical governance

All clinicians who see and plan to treat patients with skin cancer in the community should be approved by, and be accountable to, the LSMDT lead clinician, and work to agreed protocols.

The work carried out should be audited on a regular basis and staff and resources made available for this. The LSMDT/SSMDT should be responsible for how these audits are organised and carried out. All doctors and nurses should have regular CPD and would be expected to attend the LSMDT/SSMDT meetings whenever one of their patients is being discussed, and at least four times a year. In addition, meetings to discuss audit results, guidelines and cancer measures should be arranged twice a year and all team members should attend these at least once year.

³⁴ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

³⁵ British Association of Dermatologists (1999) *Guidelines for the management of basal cell carcinoma*. Available from: www.bad.org.uk/healthcare/guidelines

³⁶ British Association of Dermatologists (2002) *Multiprofessional guidelines for the management of the patient with primary cutaneous squamous cell carcinoma*. Available from: www.bad.org.uk/healthcare/guidelines

³⁷ British Association of Dermatologists (2002) *UK guidelines for the management of cutaneous melanoma*. Available from: www.bad.org.uk/healthcare/guidelines

³⁸ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

B. Anticipated benefits

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

*Organisation of skin
cancer services*

At present, the service for patients with skin cancer is fragmented. Many patients are managed by GPs or a range of hospital practitioners who do not have a special interest in skin cancer. Consolidation of care into the hands of trained personnel working within approved structures and to network-wide evidence-based clinical protocols, who subject their work to audit, should ensure that every patient receives appropriate treatment.

All patients should be treated by teams whose resources and expertise are matched to the level the patients need.

In some areas there may be a reduced use of hospital clinics for precancerous lesions and low-risk skin cancers.

Patients with low-risk lesions may be managed closer to their homes.

There will be more time and resources created for the appropriate management of high-risk cases by the specialist teams.

There will be greater standardisation of expertise and care across the cancer network.

Multidisciplinary working ensures that interventions optimise the benefit to individual patients by drawing on numerous specialisations and hence a range of viewpoints. The MDT approach is valuable in terms of support and joint learning. The inclusion of palliative care specialists, psychologists, counsellors and psychiatrists should ensure that patients' needs are met early.

An increase in the number of CNSs is anticipated to reduce patient anxiety, enhance quality of life and avoid re-admission to hospital after treatment by identifying and treating problems promptly. The CNS will have a key role in educating patients about skin self-examination in future years. Patients are likely to have more opportunity to communicate at length with the CNS, and the CNS can communicate patients' psychosocial needs and wider concerns to all involved specialties. The CNS will also ensure continuity of care between hospital and community, and primary and palliative care.

Management by efficiently coordinated MDTs, with adequate secretarial support and data management, will improve communication and coordination throughout the service. This will prevent duplication of work and help to ensure that all those involved in dealing with patients have the information they require to carry out their roles effectively.

Increased concentration of work in the hands of fewer specialists will improve the expertise of those who see more patients. This is likely to improve outcomes in all groups of patients, but particularly in those with more challenging or rarer forms of skin cancer. Staging of tumours, which is essential for treatment planning, is more likely to be accurate when clinicians are more specialised.

Management of patients within these structures will facilitate high-quality audit and research.

C. Evidence

Delay in diagnosis

Observational studies are inconsistent in their findings on the relationship between delay in presentation and the prognostic factors of melanoma tumours at diagnosis.

General practitioner

The clinical guidelines issued by NICE (*Referral guidelines for suspected cancer*) make recommendations for referral of patients with suspected cancer from primary care to specialist services. These guidelines recommend that patients presenting with skin lesions suggestive of skin cancer, or in whom a biopsy has been confirmed, should be referred to a team specialising in skin cancer.

Two RCTs demonstrated that provision of training to GPs significantly improved their ability to diagnose melanoma and NMSC, and to correctly manage patients accordingly. In one trial the training was delivered via the Internet.

Two RCTs examined the use of a diagnostic algorithm and a camera as diagnostic tools for primary care physicians treating patients with pigmented lesions suspicious of melanoma. One trial demonstrated a reduction in the proportion of excised lesions that were found by pathology to be benign, whereas the other trial found no effect.

One RCT found no evidence that giving feedback to GPs improved their ability to diagnose and manage skin cancer. However, provision of feedback was associated with an improvement in the likelihood of their including a clinical diagnosis when submitting a pathology request form.

One systematic review (of the ability of primary care physicians and dermatologists to diagnose melanoma, and to make correct decisions on biopsy and referral) included 32 primary studies, from a variety of countries. The review concluded that the data from primary studies were inadequate to show differences between dermatologists and GPs in these diagnostic and decision-making outcomes.

One systematic review of 14 US primary studies found that dermatologists performed significantly better than non-dermatologist doctors in the diagnosis of images of benign and malignant skin lesions.

In the patient survey commissioned for this guidance there was evidence that diagnosis had been delayed for a number of patients by GPs who failed to recognise the severity of the lesions or who removed lesions inadequately. The patients wanted to see improved education in skin cancer for GPs as one way of improving services.

Three observational studies found that GPs were more likely to perform incomplete excisions of melanoma tumours. One study also found that some GPs do not routinely obtain histological examination of skin lesions that they believe to be benign. Audits have shown that, when GPwSIs work to an agreed protocol dealing only with low-risk lesions, the incomplete excision rate is comparable to hospital specialty rates.

One retrospective study examined outcomes for patients with melanoma by the type of clinician performing initial treatment. This study found that, when adjusted for prognostic factors, patients treated by GPs had poorer overall survival, disease-free survival and recurrence-free interval than patients treated by dermatologists. However, these differences were not statistically significant.

In an expert paper submitted by the British Association of Dermatologists (BAD) there was support for the training of GPwSIs by consultant dermatologists in diagnostic skills for benign and malignant skin tumours. It also recommended maintaining close links with the local dermatology and histopathology departments.

Nurses

Guidelines produced by the British Association of Plastic Surgeons and the NHS Modernisation Agency recommend that more nurse specialist posts should be created and supported by adequate funding.

Observational studies of the skin cancer surveillance role of trained nurses have considerable variability but provide evidence that, after appropriate training, nurses can demonstrate high recognition rates for suspicious skin lesions.

MDT working

The benefits of the model of MDT working have been emphasised in all of the series of guidances on cancer services published by the DH and NICE. The model has been designed to meet the needs of skin cancer patients and those providing service to them. The psychosocial benefits of the services that a CNS can provide are discussed in the chapter on 'Patient-centred care' and the *Improving outcomes* guidance series, as are the benefits of the roles of members of the extended team.

Clinical guidelines produced by expert bodies in the UK support multidisciplinary care as the model of care for patients with skin cancer. UK guidelines for plastic surgery services strongly support multidisciplinary management of patients with skin lesions and recommend appropriate training and accreditation for all clinicians who perform skin surgery.

Audit evidence from the UK suggests that, to date, progress has been slow in setting up effective skin cancer MDTs that meet the standards set out in the Manual of Cancer Services Standards.

One retrospective analysis of multidisciplinary melanoma care found it to be cost-effective.

Evidence from three expert opinion articles that describe the experiences of dedicated multidisciplinary melanoma centres suggests that a multidisciplinary approach can offer further services in patient education, psychosocial support and rehabilitation. This approach is reported to increase staff enthusiasm and promote better coordination and communication via nurse coordinators, and also to improve cost efficiency. One multidisciplinary melanoma unit reported that specialist centres that treat high numbers of patients with melanoma encourage adherence to evidence-based guidance and the maintenance of standards for technically demanding surgical procedures.

One retrospective study compared pathology reports from routine pathology services with a pathology review at a multidisciplinary pigmented lesion clinic. Diagnoses were revised by the multidisciplinary clinic in 11% of all reports, and review of surgical margins led to a change in surgical margin status for 12% of patients. The study concluded that review by experienced pathologists within MDTs provides internally consistent diagnoses and valuable second opinions.

Published studies are supportive of multidisciplinary care in the treatment of special patient groups (see chapter on 'Management of special groups') and palliative care (see chapter on 'Patient-centred care').

D. Measurement

3

Structure

- A published local list of all doctors and nurses who are members of the LSMDT and SSMDT, including approved doctors working in the community. Details of their relevant expertise and training should be available at cancer network level.
- Named lead clinician for each team (LSMDT and SSMDT), agreed with the cancer network skin cancer lead clinician, and with appropriate sessional commitment.
- Evidence that each team has access to a CNS.
- Network-wide protocols for referral of patients to each level of the service and for patient management.
- Local commissioning organisations (PCTs/LHBs) providing evidence that all GPwSIs employed to carry out skin cancer work as part of the skin cancer LSMDT/SSMDT comply with the DH/BAD/RCGP guidelines and have weekly parallel clinic sessions in a hospital department with an appropriate specialist who is a member of the skin cancer LSMDT/SSMDT.
- A record of all patient information leaflets, to include information on pigmented lesions, precancerous skin lesions, BCC and any treatments offered, such as cryotherapy and PDT. These should contain photographs of skin cancers to help in self-examination.

- Audit structures in place to ensure compliance with the guidance.

Process

- Evidence that specialists attend more than 50% of all MDT meetings.
- Annual audit of attendance at all MDT meetings.
- Audit time from referral to appointment, from appointment to diagnosis and from diagnosis to treatment or referral to a hospital department (see the current national targets in the chapter on 'Patient-centred care').
- Audit of delays within the system.
- Audit of 2-week wait referrals within the system.
- Audit of the total number of patients seen by doctors working in the community and a breakdown by diagnosis and management.
- Audit of completed treatment and in particular surgical wider/re-excisions.
- Audit of excision margins according to published guidelines and the network protocol.
- Audit of the number of patients seen by a CNS.
- Proportion of cases reviewed by the MDT according to criteria listed in Tables 2 and 4.

Outcome

- Audit of surgical excision margins for all skin cancers.
- The diagnostic accuracy of cases referred from the LSMDT to the SSMDT.
- Patient outcome experience surveys including scar outcome and psychosocial adaptation.
- Audit of any complications and complaints.
- Mortality.

- Critical incidents where treatments were judged to be outside recommended network guidelines. Network meetings should take place annually to review such incidents.

E. Resource implications

Cancer networks

The main resource implications of the recommendations in this section relate to the requirement for multidisciplinary teams. Networks should establish two levels of multidisciplinary teams – LSMDT and SSMDT. Skin cancer teams are established in some but not all networks. It is estimated that 36% of all networks require at least one SSMDT or equivalent. Fifty per cent of networks require between three and six LSMDTs with a further 23% requiring a further two to four LSMDTs.

MDT provision

All costs in this section are based on the MDT meeting every 2 weeks. For those networks currently without any skin cancer MDTs in place, the opportunity cost for fortnightly MDT meetings is estimated to be between £129,134 per network ($\pm 25\%$ range, £96,851 to £161,418) and £258,268 ($\pm 25\%$ range £193,701 to £322,835).

For those networks with partial MDT provision, the opportunity cost related to forming one SSMDT would be around £49,888 ($\pm 25\%$ range, £37,416 to £62,360) and for establishing four LSMDTs would be around £105,667 ($\pm 25\%$ range, £79,246 to £132,077).

The costs are inclusive of preparation time for the lead clinician, the histopathologist, and the coordinator for the LSMDT and SSMDT, with the time also included for the radiologist at the SSMDT. The duration of the meeting has been estimated to be 2 hours.

There will be uncertainty in our estimates reflecting variation in staffing levels, preparation and actual salaries paid to individuals. Local commissioners will need to consider this further according to their existing patterns of working. There may be delays in establishing MDTs in some networks as a result of staff shortages.

It is assumed that each team will require a full-time MDT coordinator/data manager. Coordination between LSMDT and SSMDT would be part of the coordinator's role, to ensure continuity of patient care both within skin cancer teams and between skin cancer teams and, for example, head and neck cancer teams, ophthalmic cancer, soft tissue sarcomas, childhood malignancies, haematological cancers and gynaecological cancers, as well as with palliative care teams.

At present, the annual employment costs of each MDT coordinator/data manager post is £22,582. It is anticipated that an additional two to four coordinators will be required per network with employment costs of £44,470 to £88,941 per year.

Additional staff costs

Additional staff may need to be recruited to allow existing staff the time to attend meetings. Shortages of radiologists, pathologists and oncologists are likely to hinder the development and the ongoing operation of the MDTs. It is estimated that between £742,085 and £822,138 would be required per network for the annual employment of additional staff to sustain the recommendations of the guidance. This total annual network cost is inclusive of MDT coordinators and the following staff:

- four or five skin CNSs per network; annual employment cost would be between £142,330 and £177,913
- 1.75 histopathologists per network; annual employment costs of around £171,991
- 0.65 consultant dermatologists per network; annual employment costs of around £63,882
- 0.5 plastic surgeons per network; annual employment costs of around £49,140
- 0.89 radiologists per network; annual employment costs of around £87,470
- 0.97 clinical oncologists per network; annual employment costs of around £95,332
- 0.89 medical oncologists per network; annual employment costs of around £87,470

These staffing levels should be reviewed by local commissioners. Further details of the costings are in the full economic report, which accompanies this guidance.

Network-wide protocols

It is not possible to determine the cost implications of network-wide protocols, as these are dependent on clinical guidelines and may result in an increase or decrease in costs.

Clinicians working in the community

There may be resource implications for those networks that decide to provide GPwSI services in the community. The need for community skin cancer clinics will vary according to the expertise available and ease of access to local hospital departments. Some networks already have such services in place and it will be for local commissioners to decide whether to establish them. The costs have been expressed as:

- sessional rates paid to GPwSIs, inclusive of a locum
- hospital practitioner rates, and
- a more comprehensive service cost that includes GPwSI, nurse and administrator's time and consumables.

For a network to deliver 30 sessions a week for 52 weeks of the year, the annual cost of GPwSI sessional payments would be around £329,373 ($\pm 25\%$ range, £247,030 to £411,716). Thirty sessions in a network equates to 3.4 sessions per PCT/LHB. At hospital practitioner rates the payment would be £196,773 ($\pm 25\%$ range £147,580 to £245,966). The costs on a network level for the service inclusive of GPwSI, nursing time, administration and consumables is around £625,727 per network ($\pm 25\%$ range, £469,296 to £782,159). These cost scenarios have a high degree of uncertainty as they include costs for patients that have conditions other than NMCS. It needs emphasising that the costs have been presented for information purposes, and it is for local commissioners to investigate whether a GPwSI service would enhance their existing services.

At present, GPwSIs can gain training by working alongside a consultant dermatologist and/or by taking a specific postgraduate qualification. The British Association of Dermatologists recommends that 100 consultant-supervised training sessions per GPwSI are necessary to fulfil all the necessary training requirements. This is in addition to service provision time. The estimated cost for 100 training sessions with a consultant would be £18,900 for the consultant time and £21,000 for the GPwSI, inclusive of GP locum costs. The costs of a distance-learning postgraduate qualification in dermatology would be in the region of £3000 per GP. Therefore the non-recurring cost of training each GPwSI would be around £42,900. There would also be

the opportunity cost for the consultant. In future, training will have to be undertaken to the accepted level of an accredited course, examples of which will be available and will involve accreditation by all relevant parties including BAD, RCGP, patient groups and primary care society in dermatology.

It is not possible to estimate how many networks will commission GPwSI services. It is estimated that for a network with an average number of PCT/LHBs (8.78 per network), having a service involving three GPwSIs in each PCT/LHB, about 26 GPwSIs would be required, with some working part-time.

F. Research priorities

All aspects of the impact of this proposed model of care should be evaluated using appropriate research methods.

Teledermatology

Teledermatology refers to the use of digital images, together with relevant patient information, as a means of aiding referral of patients with skin problems from primary to secondary care, and it can also be used as a means of communication between specialists in secondary care (store and forward teledermatology). Real-time videoconferencing with patients from remote sites is also possible, and this guidance refers to this as a possible means of facilitating MDT work.

The evidence for the benefits of store and forward teledermatology as a means of triaging referral for patients with skin lesions is conflicting, as is the evidence regarding its cost-effectiveness. There are still many problems to be overcome before the use of teledermatology can be recommended as routine, not least the problem of ensuring patient confidentiality and the use of the Internet. It is most likely to be useful in aiding referral of patients from rural areas that may not have easy access to a specialist unit for rapid diagnosis.

The guidance recommends more research into the most effective way of utilising teledermatology to triage patients with suspicious skin lesions, looking at all aspects of its use including clinical accuracy, cost-effectiveness, patient confidentiality and patient acceptability.

Initial investigation, diagnosis, staging and management

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

*Initial investigation,
diagnosis, staging and
management*

Introduction

This chapter deals with the investigation and management of patients presenting with suspected precancerous or cancerous skin lesions. The recommendations in this chapter are consistent with and reinforce the NICE *Referral guidelines for suspected cancer*.³⁹ Most of the clinical aspects have also been well covered by recent BAD guidelines⁴⁰ on BCC, SCC and MM. These guidelines have been reviewed by the GDG, and the recommendations for referral and management for specific different tumour types in primary care have been taken into account and are summarised in Box 1 and Figure 14.

4

Investigation

Investigation is primarily by visual inspection and removal for histology where necessary. The management of skin cancer differs from that of many other cancers in that the diagnostic procedure of removing the lesion for histology is also usually the treatment. The dermatoscope is an important diagnostic aid that can be used to examine skin lesions and may make distinguishing benign from malignant pigmented lesions more accurate, but a period of training is needed for its effective use.

³⁹ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

⁴⁰ www.bad.org.uk/healthcare/guidelines

Box 1. Clinical guidelines for primary care on the management of skin cancer and precancerous lesions (see definitions of types of lesion in ‘Glossary of terms’, Appendix 6)

1. Patients with pigmented skin lesions

Patients who present to their GP with pigmented skin lesions need careful assessment with a full history and examination of the skin lesion being recorded. If the lesion is thought to be benign the patient may be reassured; however, it is strongly recommended that all such patients should be provided with both oral and written information regarding the changes that may subsequently suggest malignant transformation and instructed to return if any such changes occur or if the lesion continues to concern the patient. If there is any doubt about the lesion, or if there is a history of recent change, the patient should be referred urgently to a specialist who is a member of the LSMDT/SSMDT for further assessment (see below).

2. Patients with lesions suspicious of melanoma or SCC

All patients, where there is a possibility of a melanoma or an SCC of the skin, should be referred urgently (consistent with national targets and the NICE *Referral guidelines for suspected cancer* – see chapter on ‘Patient-centred care’), to a specialist who is a member of the LSMDT/SSMDT, usually to the local dermatology department rapid access skin cancer clinic or pigmented lesion clinic. Ideally these should be ‘one-stop’ diagnostic and treatment clinics, i.e. where a diagnosis is made and treatment given in the same clinical session. In some areas such clinics are arranged by plastic surgery units. If a GP or a doctor working in the community who belongs to an LSMDT/SSMDT takes an excisional or incisional biopsy of a lesion that is reported as a melanoma or SCC, the patient should be referred urgently to a specialist who is a member of the hospital LSMDT/SSMDT.

3. Patients with BCC

Where a patient has a lesion that may be a low-risk BCC, he or she may be referred either to the local hospital specialist who is a member of the LSMDT/SSMDT, normally a dermatologist, or to a doctor working in the community who is a member of an LSMDT/SSMDT. Those with recurrent and high-risk lesions should be treated by a hospital specialist who is a member of the LSMDT/SSMDT. If the referring GP is uncertain whether or not the lesion is a high- or low-risk BCC, the patient should be referred to a hospital specialist. Patients with BCCs are excluded from current cancer target times in England. However, the Welsh Cancer Standards for skin cancer suggest that patients should not wait more than 5 months from receipt of the GP referral letter at the hospital before starting their definitive treatment. Waiting time targets in England for all outpatient appointments will mean that from 2007 no patient will wait more than 18 weeks before being seen. Improvements in waiting time are desirable.

4. Patients with precancerous skin lesions

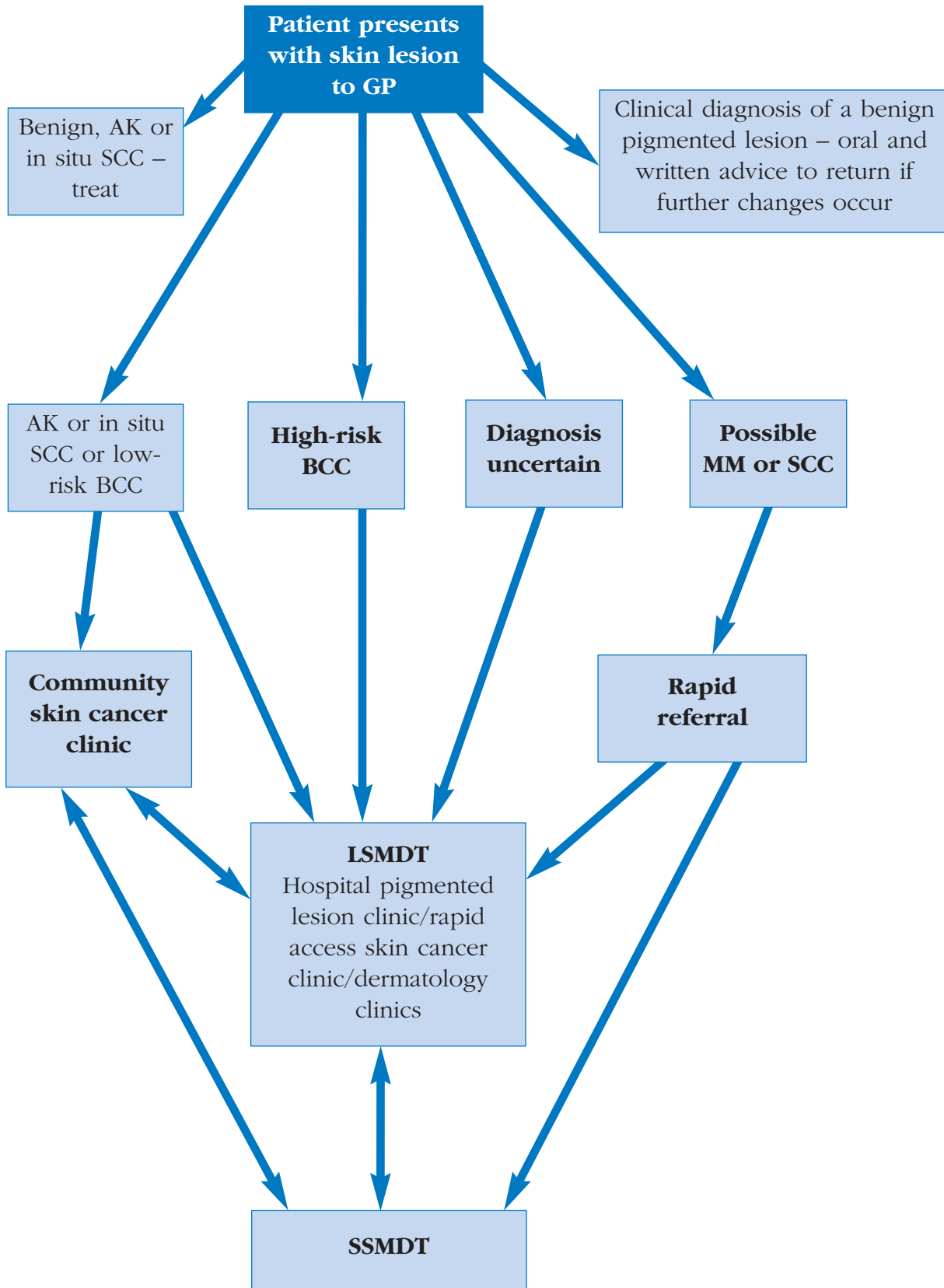
Precancerous skin lesions such as actinic/solar keratoses (AKs) or in situ SCC of the skin (Bowen’s disease) are common, and the GP may treat these using one of the recognised treatments (e.g. cryotherapy, topical drug treatments, curettage and cautery). The patient may also be referred to a doctor working in the community who is a member of an LSMDT/SSMDT or the local dermatology department. If the lesions are hypertrophic or inflamed or if there is any other reason to suspect that they may have developed into an SCC, the patient should be referred to a dermatologist who belongs to the LSMDT/SSMDT.

5. Uncertain diagnosis

If the GP is uncertain of the diagnosis the patient should be referred for further assessment to a dermatologist who is a member of an LSMDT/SSMDT.

Figure 14. Skin lesion – patient pathway

*Initial investigation,
diagnosis, staging and
management*



A preliminary biopsy may be required when a firm clinical diagnosis cannot be made by inspection alone, or when a treatment other than surgical removal is chosen for NMSC. Biopsy may also be needed before extensive surgery and in order to confirm the diagnosis in cosmetically sensitive areas such as the face. Incisional or punch biopsies should not be routinely carried out for pigmented lesions, except in exceptional circumstances. All excised skin specimens should be sent for histopathological examinations as recommended in the NICE *Referral guidelines for suspected cancer*.⁴¹ Consistency and accuracy of histopathological diagnosis are essential in achieving improved outcomes in patients with skin cancer.

Staging

For most patients with NMSC no formal staging beyond clinical examination for lymphadenopathy is required. Patients with MM may need to have more extensive investigation as described in the BAD clinical guidelines.⁴²

The major future change in the staging of MM patients is likely to be centred on the issue of sentinel node biopsy (SNB). This technique involves identifying the first lymph node draining from the tumour by scintigraphic imaging and then removing the lymph node for histological examination. In a number of countries this has become the standard of care. There is as yet no published RCT evidence that this procedure benefits patients in terms of disease-free survival. However, it is accepted that it is an important procedure for prognosis. SNB is being performed in some centres and the availability of SNB needs ultimately to be standardised across the country.

Management

Precancerous lesions

The management of precancerous skin lesions differs from the management of lesions in all other organs in that many skin lesions are treated without there being a cytological or histological diagnosis. For instance, AK and areas of Bowen's disease may be treated using non-surgical methods such as topical drug treatment, cryotherapy or

⁴¹ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

⁴² British Association of Dermatologists (2002) *UK guidelines for the management of cutaneous melanoma*. Available from: www.bad.org.uk/healthcare/guidelines

curettage (as recommended in BAD guidelines⁴³). However, patients with multiple atypical naevi and giant congenital naevi, where there is a suspicion of malignant transformation, require specialist management by the LSMDT or SSMDT. Anogenital Bowen's disease may be related to human papilloma virus (HPV) infection and also requires treatment in specialist centres.

Melanoma

The definitive treatment of primary cutaneous melanoma is a wide local excision. Excision by an appropriately trained doctor using recommended margins in accordance with guidelines is important and re-excision is performed if the margins are inadequate, as recommended by published national guidelines.

Radiotherapy has a limited role in the management of patients with MM, which is generally regarded as a radioresistant tumour. However, it may be useful and potentially curative in some patients with lentigo maligna and is occasionally used in the palliative treatment of symptomatic metastases, especially in brain and bone.

Chemotherapy is often used for patients with metastatic MM. There is no evidence to support the use of adjuvant chemotherapy following surgery. There is some evidence that interferon alfa improves recurrence-free survival, but not overall survival, when given as an adjuvant treatment after surgery. The use of vaccines is still experimental.

Occasionally, for some patients, no active treatment may be the most appropriate course of action. Supportive care and observation may be a suitable alternative in selected cases after full discussion of the options available.

In-transit metastases from malignant melanoma

Patients with in-transit metastases have a poor prognosis, with a 5-year survival rate of only 25%. Treatment for many patients is therefore essentially palliative.

Treatment options include surgery and intra-lesional therapy for individual lesions. Carbon dioxide laser therapy is valuable for multiple small-volume deposits that are too numerous to excise individually.

⁴³ British Association of Dermatologists (1999) *Guidelines for the management of Bowen's disease*. Available from: www.bad.org.uk/healthcare/guidelines

Isolated limb perfusion (ILP) may be an option for selected patients, especially those at risk of limb loss, with remission rates of up to 60% for periods of up to 2 years but with a small risk of serious morbidity. This option should be reserved for advanced in-transit disease when simpler and safer methods have been exhausted. Isolated limb infusion (ILI) is a relatively new technique that appears to be of equal efficacy; it is less invasive and easier to repeat, but toxicity is similar to ILP. Worldwide there is less experience of ILI than of ILP. Correspondingly, there is less evidence available for ILI than for ILP. Both methods are occasionally used to treat other types of skin cancers and sarcomas.

Non-melanoma skin cancer

The standard effective treatment is surgical excision and all excised specimens should be sent for histopathological examination. However, there are a range of other surgical and non-surgical procedures, which are well described in clinical guidelines. Where the other non-surgical treatments exclude histological confirmation of the diagnosis, an incisional biopsy for confirmation of the diagnosis should usually be obtained before treatment.

Other surgical and non-surgical procedures include:

- **Curettage and cautery/electrodesiccation.** This technique is performed using a curette to remove soft material from the tumour. The base of the tumour is then destroyed, using either hyfrecation or cautery. This may be used to treat small (less than 1 cm) primary BCCs, in situ SCCs and AKs. It is safe and well tolerated, and usually produces a good cosmetic outcome. It is suitable for patients with multiple lesions. However, the histology may be difficult to interpret as the lesion may be incompletely removed and margins of excision cannot be assessed optimally.
- **Cryotherapy/cryosurgery.** Cryotherapy is the destruction of skin lesions using liquid nitrogen. It is a cost-effective treatment and is well established for small lesions including AK, superficial BCC and in situ SCC. However, histology is not available unless an incisional biopsy is taken first.
- **Topical treatment.** Imiquimod (Aldara 5% cream). This is a new immune-response-modifying agent that has recently been licensed for the treatment of small superficial BCCs.

Fluorouracil (Efudix 5% cream). This is licensed for 'superficial malignant and precancerous skin lesions'.

Diclofenac 3% gel (Solaraze) is licensed for the treatment of AK. This is a widely used treatment for AK, with a favourable tolerability profile for primary care use.

- **Photodynamic therapy (PDT).** PDT involves the use of light therapy in combination with a topical photosensitising agent to destroy cancer cells. Its use has been well described in the treatment of AK, in situ SCC and superficial BCC. The advantages of PDT include a low rate of adverse effects and good cosmesis. The disadvantages are that the patient has to be available for a period of at least 3–4 hours for treatment, and that the photosensitiser and equipment are relatively expensive. A role for systemic PDT is being explored. At present there is little information available on long-term cure rates.
- **Mohs micrographic surgery.** Mohs micrographic surgery is a precise technique in which excision of the skin lesion (usually a BCC) is carried out in stages and each stage checked histologically. It is advocated for use in cases where it is critical to obtain a clear margin while preserving the maximum amount of normal surrounding tissue, in particular for recurrent and high-risk aggressive growth pattern BCCs such as morphoeic-type BCCs. The main problems with this technique include the length of the procedure, the need for special equipment and training, and the relatively high cost. The availability of the procedure in the UK is, at present, limited.
- **Radiotherapy.** Radiotherapy is a useful treatment for a subset of patients with NMSC who cannot or prefer not to be treated by surgery. The cure rates are over 90% for most skin lesions, but the long-term cosmesis, particularly for young patients, is inferior to that following other treatments. The same area cannot be treated twice and so, if there is a recurrence, surgery is needed, which may be more difficult than if the lesion had been removed surgically to start with. Radiotherapy can also be used in cases when the margins of excision appear to be incomplete on histopathological examination. It should not be used to treat patients with Gorlin's syndrome because of the carcinogenic potential of low-dose irradiation at the margins of the treated areas.

Traditionally radiotherapy for skin cancer has been given with superficial (orthovoltage) X-ray machines. High-energy electron (linear accelerator) treatments are increasingly being used, but orthovoltage treatment may be easier to use for small tumours and for frail patients. It is therefore important that radiotherapy departments continue to provide access to such machines.

Radiotherapy is curative for some cases of advanced inoperable disease. Radiotherapy also has a role in the palliative treatment of patients with large, inoperable and recurrent SCC, or if there are inoperable metastases in lymph nodes or elsewhere.

Radiotherapy has a role in adjuvant treatment of extracapsular nodal disease following neck dissection, for example, and not just palliation.

- **Systemic treatment.** There are very few patients with NMSC who need systemic treatment with chemotherapy.

A. Recommendations

Investigation and diagnosis

GPs should receive training as recommended in the NICE *Referral guidelines for suspected cancer*⁴⁴ on the diagnosis of precancerous and cancerous lesions, and should receive feedback through audit on their diagnostic accuracy.

GPs should refer certain groups of skin lesions as described in Box 1 and Figure 14 directly to an LSMDT without biopsy. This practice should be subject to audit.

All excised skin specimens should be sent for histopathological examination as recommended in the NICE *Referral guidelines for suspected cancer*.⁴⁵

Dermatoscopy should be available in all MDTs, but its use requires training.

There should be equity of access so that all tissue samples are reviewed in high-quality histopathology services. Accurate diagnosis in dermatopathology depends on clinicopathological correlation, involving input from both clinician and pathologist. Although this can be achieved in difficult cases by interspecialist discussion or seeing the patient records, in some instances (such as cutaneous lymphoma) it may be essential for the patient to be seen jointly. Accordingly, for good clinical governance, it is recommended that the histopathology reporting of any specimens likely to be considered by a skin cancer MDT should be undertaken in a laboratory having easy access to relevant clinicians, patient records and the attending patient.

⁴⁴ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

⁴⁵ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

Histopathology services for skin cancer should be part of a managed pathology network or equivalent model.

Histopathology reporting should be provided by histopathologists who participate in EQA. This may be a general histopathology EQA scheme that includes skin or a more specialist skin EQA scheme. When appropriate, the EQA scheme should cover lymphoma. Given the overlap with head and neck cancer services, it should be noted that the head and neck histopathology EQA scheme includes skin cases.

All histopathology reports relating to skin cancer should conform to the Royal College of Pathologists minimum datasets⁴⁶ on cancer in order to provide adequate and appropriate information on prognosis, planning individual patient treatment, supporting epidemiology and research, and to evaluate clinical services and support clinical governance.

SNB samples for skin cancer should be examined and reported by specialists with a registered qualification in histopathology. It is desirable that SNB samples resulting from skin cancer are handled and reported by the same team of pathologists involved in the reporting of skin cancer. The technical processing of SNB samples must conform to recognised national or international protocols (such as that used by the European Organisation for Research and Treatment of Cancer (EORTC)⁴⁷).

All MMs and severely atypical naevi should be double-reported if resources allow the report to be generated within 2 weeks. The acknowledged current shortfall of an NHS histopathology workforce in some centres could delay this quality recommendation. Although it is ideal that all melanocytic lesions are double-reported to avoid missing MM, it is likely to be many years before the NHS histopathology workforce could achieve this.

Given an adequate histopathology workforce in the medium to long term, it is desirable that eventually all skin cancers are double-reported to achieve consistency and accuracy in diagnosis. It is also recognised that alternative models to double-reporting of MM exist, such as consensus meetings outwith the MDT. These are equally acceptable so long as all potential MDT cases are discussed and the meetings formally minuted with regard to attendance and diagnosis.⁴⁸

⁴⁶ Royal College of Pathologists. *Standards and datasets for reporting cancers*. Available from: www.rcpath.org

⁴⁷ www.eortc.be

⁴⁸ Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk

All cases referred to the SSMDT should have a specialist histopathology review.

An appropriately resourced national system for histopathology tertiary review should be established. Currently, several thousand complex and/or rare skin cancer cases per year require tertiary opinions from a small number of informally recognised national expert specialist dermatopathologists. Even with the formation of larger pathology networks, the complexity of these cases indicates that this tertiary referral practice will continue to be necessary to obtain the correct diagnosis and thereby maximise the quality of patient treatment and care. All SSMDT cases falling into this category should have full access to this tertiary referral facility when supported by the SSMDT. Commissioners should be aware of the funding implications. These services, which may cross many network boundaries, should be commissioned through the specialised services commissioners.

MDTs should complete the national cancer datasets for common skin cancers and for lymphoma.^{49,50}

Management of precancerous lesions

Where there is any doubt about the diagnosis, the patient should be referred for a specialist opinion as described in Box 1 and Figure 14.

All excised skin specimens should be sent for histopathological examinations as recommended in the NICE *Referral guidelines for suspected cancer*.⁵¹

Patients with two or more atypical naevi, and giant congenital naevi where there is a suspicion of malignant transformation, and who need assessment and education should be referred to a member of the LSMDT or SSMDT (see chapter on 'Organisation of skin cancer services', Table 2 and Table 4).

Medical photography has a special role to play in surveillance for patients with atypical naevi. Therefore all departments treating skin cancer should have access to high-quality medical photography and storage of digital images.

Any doctor or nurse who knowingly treats patients with precancerous lesions should have received locally approved training in available treatments.

⁴⁹ Royal College of Pathologists. *Standards and minimum datasets for reporting cancers*. www.rcpath.org

⁵⁰ www.icservices.nhs.uk/cancer/pages/dataset/default.asp

⁵¹ National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

Patients with anogenital Bowen's disease (including penile and vulval) should be referred to relevant specialist centres, and this may include referral to a urologist, gynaecologist or coloproctologist, depending upon local expertise.

Any patient with a lesion suspected of being lentigo maligna needs to be referred to and managed by a hospital-based member of an LSMDT/SSMDT.

All treatments identified in this chapter for the treatment of precancerous lesions should be available for use by clinicians in all of the teams, subject to locally agreed standards of competence.

Management of skin cancers

All excised skin specimens should be sent for histopathological examinations as recommended in the NICE *Referral guidelines for suspected cancer*.⁵²

Only doctors and nurses who have received locally approved training and who are active members of a skin cancer MDT should carry out surgery for skin cancers. Scar placement and management should be considered before surgery.

Mohs surgery should be available in each cancer network and only carried out by those who have received training approved by the lead clinician of the skin cancer site-specific network group.

Patients should be given information and be involved in decision-making, as set out in the 'Patient-centred care' chapter.

SNB should only be undertaken in centres where there is clinical experience of the procedure and normally only within the context of ethics-committee-approved clinical trials. However, in order to maintain their already established expertise, centres may continue to offer SNB between trials.

Chemotherapy should be available for the management of skin cancer patients where appropriate.

Adjuvant alfa interferon treatment should only be given as part of a clinical trial.

⁵² National Institute for Health and Clinical Excellence. *Referral guidelines for suspected cancer*. Available from: www.nice.org.uk/CG027

Treatments using surgery and carbon dioxide laser techniques should be available at regional centres via SSMDTs, but ILP and ILI would only be required at supraregional centres.

Vaccine therapy for advanced MM remains uncertain and its use should only be in the context of a clinical trial.

Before non-surgical treatment, a tissue sample for confirmation of the diagnosis should usually be obtained.

Histopathology services should be adequately staffed and resourced to cope with the potential increase in skin biopsies resulting from the recommendations in this guidance. Commissioners should note, however, that acknowledged current workforce shortages could delay this implementation.

NHS histopathologists in England and Wales must work in laboratories that are seeking or have accreditation with Clinical Pathology Accreditation Ltd.

All cancer networks should have easy access to appropriate immunophenotypic, molecular biological and cytogenetic facilities. Some of the latter are very specialised pathology services and may not be provided by pathology laboratories within the LSMDT or SSMDT.

Cancer networks should identify one or more clinical oncologists and medical oncologists with responsibility for the radiotherapy and systemic treatment of patients with skin cancer.

Radiotherapy departments should have the appropriate equipment including orthovoltage radiotherapy machines for the management of patients with skin cancer.

All treatments identified in this chapter for the treatment of skin cancer should be available for use by clinicians in all of the teams, subject to locally agreed standards of competence.

B. Anticipated benefits

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

Better-quality diagnosis and treatment by trained and audited personnel should result in better outcomes for patients.

*Initial investigation,
diagnosis, staging and
management*

The benefits of giving patients adequate information, breaking bad news sensitively, and providing support at the crucial time of diagnosis are well documented. These issues are further discussed in the 'Patient-centred care' chapter and in the NICE guidance *Improving supportive and palliative care for adults with cancer*.⁵³

There will be greater accuracy in reporting of MM.

Adjuvant therapy will predominantly be performed in the context of clinical trials in order to increase knowledge of the efficacy of treatments.

SNB will only be performed in centres with expertise in the context of clinical trials, thereby ensuring that the technique will be properly evaluated.

Increased access for Mohs surgery will improve outcomes for some patients.

C. Evidence

Pathological diagnosis

There is evidence from observational studies indicating that not all tissue samples are sent for pathology reporting.

There is evidence from observational studies that there are discrepancies between general pathologists and specialist dermatopathologists and specialists in pigmented lesion pathology in the reporting of melanomas and other pigmented skin lesions.

Observational studies provide evidence that histopathological examination has high sensitivity and specificity for melanoma. These studies also report difficulty with diagnostic accuracy and consistency for melanocytic lesions that are considered borderline for malignancy. Other lesions that are reported as presenting difficulty for pathological diagnosis include childhood melanoma, atypical naevi and Spitz naevi.

⁵³ National Institute for Clinical Excellence (2004) *Improving supportive and palliative care for adults with cancer*. Available from: www.nice.org.uk

There is evidence from audits of discrepancies between diagnoses made by local clinicians and specialists in the field of lymphoma. This is referenced in the NICE Guidance on Cancer Services *Improving outcomes in haematological cancers*, which states that approximately one quarter of lymphoma reports have this discrepancy.

Dermatoscopy

One RCT found that, following a brief training intervention for GPs in the use of dermatoscopy, there was a significant improvement in the accuracy of clinical diagnosis of melanoma and in the diagnosis of melanoma using dermatoscopy. The improvement was significantly greater for the use of dermatoscopy than for clinical diagnosis.

Three systematic reviews and one case series provide evidence that hand-held dermatoscopy improves diagnostic accuracy as compared with unaided examination. There is evidence from one systematic review that the diagnostic accuracy of dermatoscopy depends on the degree of experience of the examiner.

Teledermatology

One RCT compared teledermatology with face-to-face consultation as a method of examining patients with skin lesions at a dermatology department. All patients received a further, independent face-to-face skin examination with a consultant dermatologist. For each randomised group, concordance between the two consultations for each patient was measured, primarily for management plan and secondarily for diagnosis. There was significantly greater concordance between consultations for management plan and for diagnosis in patients randomised to face-to-face skin examination than in those randomised to teledermatology. No difference was detected between randomised groups for patient satisfaction.

One RCT compared two types of teledermatology (by live videoconference and by sending still photographic images) with traditional outpatient consultation, as methods for GPs to refer patients to dermatologists. The dermatologist requested a subsequent hospital appointment for 69% of patients examined by the still image method, compared to 46% of patients examined by videoconferencing and 45% of patients examined in person.

One RCT compared teledermatology with standard referral and found that patients in the teledermatology group received definitive treatment significantly more quickly than patients in the standard referral group. Teledermatology patients were significantly more likely to avoid the need for a further clinic visit compared with control patients.

One RCT compared teledermatology consultation using a videolink with outpatient consultation and found no difference between the groups in the reported clinical diagnoses.

One RCT of teledermatology compared to traditional consultation found no significant difference between groups for patient satisfaction with either their care or the management of their skin problems, and 85% of the telemedicine patients reported that they would use the system again.

Two systematic reviews suggest that there is no consensus from primary studies on whether teledermatology is more cost-effective than traditional management of dermatology patients.

Audit data from the UK indicates that GPs report quicker referral of dermatology patients through teledermatology.

Imaging techniques

Evidence-based guidelines from the UK recommend that imaging is not normally indicated in the initial assessment of patients with primary melanoma except for clinical investigation of symptoms or signs.

One systematic review and meta-analysis of the role of positron emission tomography (PET) in detecting metastatic melanoma estimated sensitivity as 0.79 [95% CI 0.66–0.93] and specificity as 0.86 [95% CI 0.78–0.95].

Evidence from observational studies suggests that PET has the ability to detect surgically resectable metastases earlier than conventional imaging but is inferior to CT or MRI in detecting pulmonary and hepatic metastases from haematogenous spread.

Evidence from a systematic review and meta-analysis suggests that ultrasound imaging has significantly higher discriminatory power to evaluate the status of lymph nodes in patients with melanoma, compared with palpation alone.

Evidence from observational studies does not support widespread, routine use of CT in the management of patients with melanoma, but supports consideration of CT on an individual basis.

Surgical therapies

Surgical excision is the standard therapy for the great majority of skin cancers.

Evidence-based guidelines from the UK recommend that lesions suspected of being melanoma are initially excised as full-thickness skin biopsies, including the whole lesion with a 2–5 mm clinical margin of normal skin laterally and with a cuff of sub-dermal fat. Histologically confirmed melanoma tumours require referral to a specialist centre for excision, with a margin of between 1 cm and 3 cm, stratified according to Breslow thickness.

Evidence from two systematic reviews suggests that in the excision of melanoma surgical margins of 3–5 cm have no advantage, in terms of local recurrence, overall survival and disease-free survival, over margins of 1–2 cm.

One RCT that compared 1 cm versus 3 cm surgical excision margins for melanoma found an advantage of borderline statistical significance in terms of locoregional recurrence for 3 cm margins over 1 cm margins, with no significant difference in survival detected.

Mohs micrographic surgery

There is systematic review evidence to support the use of Mohs surgery for large, high-risk BCCs located at surgically complex regions of the face.

Systematic review evidence also exists for the use of Mohs surgery in patients with recurrent NMSCs, in patients with tumours with aggressive growth histology and in patients with large NMSCs with indistinct margins.

Sentinel node biopsy (SNB)

No randomised controlled trials reporting on survival following SNB in patients with melanoma have been published. There is good evidence that SNB for melanoma may be useful as a staging investigation, and participation in EORTC adjuvant trials may become dependent on its availability.

One systematic review based upon 12 studies found the proportion of tumour positive sentinel nodes to be 17.8% [95% CI 16.7% to 19.0%], and this proportion correlated strongly with Breslow thickness. The authors recommended that SNB is inappropriate for tumours with Breslow thickness less than 1 mm, that for Breslow thickness between 1.0 mm and 1.5 mm SNB should be considered on an individual basis in the light of other prognostic factors and possible adjunctive therapy, and that for Breslow thickness between 1.51 mm and 4.0 mm SNB is appropriate. The authors reported that the value of SNB for Breslow thickness greater than 4.0 mm is questionable because of the high risk of existing haematogenous spread.

There is evidence from observational studies that the status of the sentinel node significantly predicts disease-free survival.

Evidence from observational studies suggests that, while surgical complications can arise from SNB, the procedure is less invasive than a regional lymphadenectomy.

The findings of observational studies are inconsistent as to whether patients with melanoma who undergo SNB show increased rates of in-transit recurrence, compared with patients who receive delayed regional lymphadenectomy after detection of clinically palpable lymph nodes.

Lymph node clearance

One systematic review found no statistically significant advantage in terms of overall mortality arising from elective lymph node dissection compared to delayed lymph node dissection at the onset of clinical symptoms.

One RCT of elective versus delayed regional lymph node dissection in patients with melanoma found that the routine use of immediate node dissection had no significant impact on survival, while the status of regional nodes significantly predicted survival.

Cryotherapy/cryosurgery

Three UK clinical guidelines produced on behalf of the British Association of Dermatologists support the use of cryotherapy in the treatment of a sub-set of patients with Bowen's disease, SCC (where good short-term cure rates are achievable) and primary BCC.

One systematic review of RCTs of treatments for BCC found that cryotherapy showed no significant difference in recurrences at one year, measured clinically, when compared to surgery. When radiotherapy was compared to cryotherapy there were significantly more recurrences at one year in the cryotherapy group.

Photodynamic therapy (PDT)

There is expert review and observational study evidence to suggest that PDT can be very effective in clearing superficial BCCs, AKs and SCC in situ (Bowen's disease), and is useful in patients who cannot undergo surgical therapy. The 2-year recurrence rate after treatment of nodular BCC of the skin is approximately 20%, and this needs to be taken into account when deciding on this treatment.

Guidelines from the British Photodermatology Group state that topical PDT is an effective treatment for patients with actinic keratoses on the face and scalp, Bowen's disease (with results comparable to fluorouracil or cryotherapy) and superficial BCC (with results comparable to cryotherapy). The guidelines also state that PDT is a relatively poor option for both nodular BCCs and SCCs.

Clinical guidelines produced by the BAD for the treatment of patients with BCC report that PDT is not yet widely used in the UK.

Radiotherapy

Clinical consensus suggests that radiotherapy still has an important role in the treatment of elderly patients, and as an alternative to mutilating surgery in the treatment of advanced disease.

One systematic review of RCTs of treatments for patients with BCC found that radiotherapy is an effective treatment, with local recurrence rates that are better than those following cryotherapy but worse than those following surgery. The authors concluded that surgery and radiotherapy are the most effective treatments for BCC.

Evidence from observational studies suggests that high rates of local and regional control can be achieved by radiotherapy for patients with NMSC, but with higher local recurrence rates for patients with SCC. Observational study evidence also suggests that in patients with BCC of the head, face and neck that are treated with superficial radiotherapy, the total local recurrence rate is approximately 6%.

Expert review evidence supports the role of low-dose radiotherapy with minimal penetration in the treatment of lentigo maligna, with control rates of 95–100%.

Expert review evidence suggests that in patients with melanoma, radiotherapy can reduce the rate of local-regional recurrence of melanoma when given as an adjunct to surgery following excision of aggressive or recurrent tumours, or as an adjunct to regional lymph node dissection. Radiotherapy has a palliative role in treating patients with metastatic melanoma.

Topical therapy

Imiquimod

The results of two RCTs comparing imiquimod with inert vehicle indicate that imiquimod is an effective treatment for superficial BCCs. A Cochrane review reported that the imiquimod trials do not have long-term follow-up, and so the rate of recurrence of BCCs treated with imiquimod is not known. There is also no evidence for the comparison of imiquimod with surgery. The authors concluded that if longer-term trials confirm the initial experience reported in these trials, imiquimod would be an effective treatment for superficial and low-risk BCCs.

Fluorouracil

Evidence from expert reviews suggests that topical fluorouracil can eradicate actinic keratoses, with cure rates of 43–93%. The same level of evidence suggests that skin irritation is a common side effect that can be controlled by using a less frequent dose or by applying topical corticosteroids

Diclofenac

Two RCTs have compared topical 3.0% diclofenac in 2.5% hyaluronate gel, with 2.5% hyaluronate gel alone as placebo, in the treatment of patients with actinic keratosis. One study used 60 days of treatment and the other used 90 days of treatment. The studies used the same objective and subjective scoring systems to evaluate the response of the lesions at 30 days after treatment. In both studies significantly greater proportions of patients in the active treatment groups than in the placebo groups reached threshold values of improvement on the scoring systems.

One case series study of patients diagnosed with AK found that topical treatment with 3% diclofenac for 90 days resulted in lesion improvement at the assessment point at 30 days after treatment, as measured by objective and subjective scoring measurements.

Systemic therapy

Dacarbazine

One systematic review concluded that there is no evidence from RCTs to show superiority (in terms of survival, quality of life, tumour response rates and toxicity) of systemic therapy over best supportive care/placebo in the treatment of patients with melanoma. The authors noted that dacarbazine, when used alone, has partial responses in 15–28% of patients, complete responses in 3–5% and long-term remission in less than 2% of patients.

One systematic review of RCTs concluded that in patients with advanced-stage melanoma no polychemotherapy schedules were found to significantly prolong overall survival compared to dacarbazine and that the use of interferon alfa in adjuvant therapy increased disease-free survival.

One meta-analysis, which compared single agent dacarbazine with any chemotherapy combination in patients with stage IV melanoma, concluded that the combination of dacarbazine and interferon alfa is more effective than standard single-agent dacarbazine in terms of tumour response rates. No difference in overall survival was demonstrated.

Interferon alfa

A meta-analysis of RCTs comparing interferon alfa with control in the adjuvant setting found that recurrence-free survival was significantly improved with interferon alfa, but with no significant difference in terms of overall survival. A significant dose-response relationship for recurrence-free survival was observed, but not for overall survival.

A systematic review of RCTs of interferon alfa in patients with stage I or II melanoma concluded that, of nine trials, only one adequately demonstrated a statistically significant benefit in disease-free survival for the patients treated with interferon alfa, and that there is no evidence for increased overall survival arising from interferon alfa.

A meta-analysis found that the use of interferon alfa as an adjuvant therapy for patients with surgically treated melanoma significantly reduced the relapse rate at high and low dose, although no significant effect was found in terms of overall survival.

Immunotherapy

An RCT comparing allogeneic melanoma vaccine versus observation in patients with surgically treated melanoma found no significant difference in disease-free survival between randomisation groups, nor between patients with thick (> 3 mm) versus thin (\leq 3 mm) tumours.

A small RCT comparing vaccine therapy with placebo concluded that immunisation with a melanoma vaccine was able to slow the progression of melanoma with reduced time to recurrence. No significant effect was observed for overall survival.

In-transit melanoma

Evidence from one systematic review of RCTs suggests that ILP with melphalan can be used as a treatment for local disease control of in-transit melanoma where other forms of locoregional therapy are not suitable.

Palliative and supportive care

There is a lack of good-quality evidence on the specific service requirements for palliative care of patients with skin cancer. The evidence for supportive care has been reviewed in the 'Patient-centred care' chapter.

The evidence for the requirements for adult cancer patients and their carers is reviewed in the NICE Guidance on Cancer Services *Improving supportive and palliative care for adults with cancer*.

Evidence for the requirements of children and young people with cancer is contained in the NICE Guidance on Cancer Services *Improving outcomes in children and young people with cancer*.

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

*Initial investigation,
diagnosis, staging and
management*

D. Measurement

Structure

- Written protocols, agreed by all MDTs in the network, which specify investigations and management for each type of presentation of potential skin cancer.
- Locally approved training courses for GPs in the diagnosis of skin lesions.
- Locally approved training courses for skin surgery for any practitioner who undertakes this in the community.
- Availability of written information for patients about their cancer, proposed interventions, and hospital and support services.
- Access to orthovoltage radiotherapy machines.
- Audit of availability of high-quality medical photography and storage of digital images.

Process

- Time between first GP consultation with sign/symptoms of skin cancer and histological confirmation of diagnosis.
- Evidence that all tissue samples from possible cancers are sent to a designated pathologist with expertise in identification of skin cancer.
- Audit of visual diagnostic accuracy to compare clinical and histopathological diagnoses.
- Audit of adequacy of resection.
- Time between initial investigation and definitive diagnosis.
- Audit of visual diagnostic accuracy.
- Audit of adequacy of resection.
- Surveys of time to first definitive treatment in line with national targets (see section on 'Cancer waiting time targets').
- Surveys of patients' and carers' views.

- Adherence to treatment protocols (radiotherapy, chemotherapy and other treatments), and adherence to individual treatment plans.

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Outcome

- Reduced time to diagnosis.
- Improved patient experience.
- Services adapted to evidence obtained from surveys of patients' and carers' views.
- Improved visual diagnostic accuracy in relation to histopathological finding as gold standard.
- Reduced local recurrence rate.
- Better survival in MM.
- Reduced time to definitive surgery.

4

E. Resource implications

Investigation and diagnosis

The main resource implication of the recommendations concerning the investigation and diagnosis concerns the additional role for histopathologists. The increased workload has been calculated taking account of LSMDT and SSMDT working, implementation of the minimum dataset, doubling the reporting of severely atypical naevi, and MM and SSMDT mandatory review. Approximately two-thirds of the additional workload relates to SSMDT and tertiary review. It is estimated that approximately 1.75 additional consultant histopathologists/dermatopathologists would be required per network to support the guidance. In addition, there would be an additional requirement for laboratory staff, not calculated here. The additional annual employment costs of the histopathologists will be around £171,991 per network. (This cost has been included in the total cost for additional staff required as a result of the guidance, reported in the 'Organisation of skin cancer services' chapter.)

Management of precancerous lesions

The cost implications of training GPwSIs have been considered in the 'Clinicians working in the community' section. The British Dermatological Nursing Group recommends courses for nurses who wish to undertake further training to become specialists in dermatology and in skin cancer. They are either first degree or masters level modules; examples include minor surgery, managing patients with pigmented skin lesions and phototherapy. Some courses are available as distance-learning modules. Costs for specialist modules range between £350 and £791 per module (mean £570). For existing staff these costs would be part of annual CPD.

Management of skin cancers – Mohs

The recommendation that will have a significant cost impact in this section relates to the training of Mohs surgeons. Currently dermatologists, or other consultants, can train with an expert in the technique for 3 months in the UK. There is no charge for this training at present. Three months' salary for a consultant undergoing the training, including oncosts, for 2005/06 is around £24,570. There is also a 12-month Fellowship Program in Mohs surgery in the United States. The consultant's employment costs would be around £98,280 for 12 months. Other training options are available in Lisbon.

In order for there to be one Mohs specialist per network, the estimated employment cost will be between £24,570 and £98,280 per network currently without such expertise. Additional funds would be needed for locum cover while the consultant is training. However, this would not be an immediate cost as there are limited numbers of trainee placements available each year. In addition to the direct cost, there is an opportunity cost for the consultant delivering the training.

The introduction of Mohs surgery also has significant cost and staffing implications for histopathology services. As well as laboratory facilities, this includes staffing at both biomedical scientist and consultant histopathologist levels. These must be taken into account in the commissioning of a new Mohs surgery service. Detailed costings for the Mohs service, with histopathology, have not been included in the guidance as they are variable depending on the local model of Mohs surgery introduced.

F. Research priorities

- Given the enormous service burden associated with treatment of skin tumours, there is a lack of good-quality research on the efficacy of the treatment modalities used.
- Studies with long-term follow-up are needed to examine the benefits of excisional surgery of NMSC compared with those of other treatments available.
- Further research on systemic PDT is needed before it can be recommended.

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*Initial investigation,
diagnosis, staging and
management*

Introduction

This chapter deals with follow-up of the majority of patients with skin cancer who do not fall into the groups cited in the 'Management of special groups' chapter who may have more intensive follow-up needs.

This chapter does not deal with follow-up of patients with precancerous lesions, because once the diagnosis and education have been given to the patient, no further follow-up is indicated. Following consultation, some patients with multiple lesions and those with continually developing lesions may need longer-term follow-up, and this should be at the discretion of the doctor in charge of the management of the patient. Follow-up of these patients may not necessarily have to be made in a local hospital, and arrangements will depend on local circumstances and patient choice.

Although a large proportion of patients report that they value follow-up, it does cause anxiety in many, and some patients find that attending for follow-up makes it difficult for them to return to 'normal life'. These patients may prefer not to attend but currently feel that they do not have this choice. Options and decisions regarding follow-up should be agreed jointly with the patient.

The importance of follow-up varies across skin cancer types, depending on the risk of recurrence, the efficacy of intervention in recurrent disease, the risk of development of metachronous (new primary) disease and the methods for detecting this. Follow-up by doctors or nurses is only of benefit if it leads to detection of recurrent or new disease at a point in time when intervention is more likely to be effective than when patients present, having become aware of the problem themselves. In skin cancers with a low risk of mortality or recurrence (e.g. low-risk BCCs), long-term follow-up is not cost-effective. The net benefit for patients in terms of reassurance is poorly understood.

For patients with low-risk BCC or SCC the majority of recurrences can be cured if identified early. In addition, patients with low-risk BCC or SCC are at low risk of recurrence and extremely low risk of mortality, and the majority of these patients will be suitable candidates for self-follow-up. Clinicians should be aware that, because of their mental or physical state, not all patients will be able to perform self-examination.

Ideally, RCTs of the effectiveness of prolonged follow-up should be the gold standard against which decisions on follow-up strategy are made. In the absence of these, the factors that need to be taken into account are:

- the risk of recurrence or development of metachronous (new primary) disease
- whether there is any evidence that clinicians detect recurrent or metachronous disease at an earlier stage than patients, whether treatment of this earlier stage disease is more effective, and whether patients can be trained to detect recurrence or new disease as well as doctors.

Follow-up of skin cancer patients accounts for a significant proportion of outpatient clinic time. The main aims of follow-up are different in the immediate post-treatment phase and in the longer term. Short-term follow-up (less than 6 months) is important for:

- patient education, especially regarding sun protection measures and early recognition of new and recurrent lesions
- provision of help, and rehabilitation for patients suffering from complications and side-effects of treatment, e.g. scars, lymphoedema
- provision of psychological and emotional support to patient, carer and family
- the evaluation of surgical outcome through audit.

Long-term follow-up (more than 6 months) is usually aimed at:

- identifying locoregional or distant recurrence
- identifying metachronous disease.

The Cancer Services Collaborative Project in England⁵⁴ has shown that the perceived need for lifetime follow-up of cancer patients in hospital clinics can be challenged by a review of the evidence. With appropriate education and training, patients can be discharged to active self-follow-up, releasing significant capacity in outpatient clinics for the management of new patients.

Patients with precancerous and cancerous lesions of the skin are extremely numerous and the vast majority will not die of their disease. Although the risk of metachronous disease for patients presenting with cancer is high, for most patients follow-up will make no difference to survival, although later presentation may result in more extensive treatment and related morbidity. It is therefore essential that only those patients who will benefit be recalled for doctor- or nurse-based follow-up. This will include patients with:

- advanced-stage disease at presentation
- disease for which the management is difficult
- a high risk of developing recurrent disease
- a high risk of developing metachronous tumours
- failure to respond to the initial treatment
- lesions at sites that are difficult to examine.

Reducing the number of patients attending for formal follow-up will improve the capacity to provide high-quality treatment to the ever-increasing numbers of new patients and patients re-presenting with metachronous lesions. Moreover, as the skin is visible to patients and carers, most can be trained to identify new lesions.

A. Recommendations

Cancer networks should develop locally agreed protocols for follow-up of each skin cancer type, taking into account national guidelines, the risks of local recurrence, metastatic spread and new primary lesions.

⁵⁴ www.aswcs.nhs.uk/aswcs/csc/default.htm

Follow-up for patients after treatment for skin cancer should be tailored, as much as possible, to the individual, taking into account the patient's needs and wishes. Options and decisions regarding follow-up should be made jointly with the patient.

All patients should be given both oral and written information about the different types of skin cancer and instruction about self-surveillance.

All patients should be given written instruction on how to obtain quick and easy access back to see a member of the LSMDT/SSMDT when necessary. GPs should be given advice about local arrangements for patients to re-access skin cancer services.

Follow-up arrangements may include a combination of self-surveillance, GP or other community doctor, and specialist nurse or hospital specialist clinic.

Some patients, such as those who are immunocompromised or who have a genetic predisposition to the development of skin cancers (e.g. Gorlin's syndrome, xeroderma pigmentosum), may need lifelong surveillance (see chapter on 'Management of special groups').

Positron emission tomography (PET) scanning is not routinely recommended for follow-up; however, it may be useful for a small number of patients with suspected recurrent disease when clinical doubt remains after other forms of imaging. PET scanning should therefore be available on a supraregional basis for these patients.

Basal cell carcinoma and squamous cell carcinoma

Patients with BCCs or SCCs, with a low risk of recurrence, do not need long-term surveillance and should be discharged from formal follow-up, but should be given information and instruction as recommended above.

Patients who are at high risk of recurrent or metachronous cancer or who find self-examination difficult require formal follow-up. The period of time and frequency will depend on the degree of risk, which should be discussed with the patient. This may be particularly important for patients with high-risk SCCs, because of the more serious implications of locoregional recurrence.

Melanoma

Patients with in situ MM do not require follow-up, but should be given information and instruction as recommended above.

Patients with invasive MM should have a period of formal follow-up, the frequency and duration of which depends on the risk of metastatic spread and which should take into account the patient's psychological and emotional needs. Detailed recommendations for patients are made in the BAD guidelines for MM.⁵⁵

Patients who have had multiple primaries or those with a family history of MM require long-term follow-up, sometimes lifelong.

B. Anticipated benefits

The anticipated benefits of these recommendations for follow-up tailored to patients' risks are that some patients will be reassured by receiving training in prevention and recognition of new suspicious lesions. These patients will then be discharged to active self-surveillance with the contact details for rapid re-entry into the system, if they have concerns. This process may also free up more clinic capacity for the management of patients at high risk of recurrence or metachronous disease. The problem of the increasing workload of new patients or patients returning with metachronous lesions, reflecting the increasing incidence of both of these, may also be addressed.

For patients at increased risk of recurrent disease, as described above, a structured follow-up programme may result in earlier detection and better outcomes. Recurrent disease is often treatable, although more challenging to treat than primary disease. Access to appropriate MDTs will ensure that patients receive the expert help they need. Increased availability of a high level of diagnostic expertise and specialist imaging will ensure better access to appropriate treatment. The CNS contribution to the decision-making process about the most appropriate follow-up for individual patients, based on their psychosocial as well as their physical needs, can be particularly valuable.

Patients with NMSC may be entered into clinical trials and studies. It is important that these patients have adequate follow-up in order to produce meaningful and useful data. Inadequate follow-up is a frequent problem in skin cancer research.

⁵⁵ British Association for Dermatologists (2002) *UK guidelines for the management of cutaneous melanoma*. Available from: www.bad.org.uk/healthcare/guidelines

C. Evidence

Evidence exists that early detection of skin malignancy or its recurrence reduces the extent and adverse effects of treatment and the more serious regional or systemic metastatic development. However, there is little evidence except in the case of MM and advanced SCC to support long-term follow-up.

Basal cell carcinoma

Current evidence-based recommendations from the BAD guidelines advise that long-term hospital-based follow-up after treatment of BCC for patients other than those with Gorlin's syndrome is neither necessary nor recommended. For a small number of selected patients follow-up can be important, but there is no clear consensus on selection criteria for these patients or the frequency or total duration of such review.

Analysis of observational studies indicates that the risks of developing a metachronous BCC in a patient who has already had one treated range from 16% to 36% at 1 year, rising to a 36% to 50% risk at 5 years. There is an increased risk of developing new BCCs in patients who present with multiple skin cancers, in men, and in those whose skin does not tan and who have a history of frequent sun exposure.

One systematic review found the recurrence rate of BCC to be 4.2% in studies reporting less than 5 years' follow-up and 8.7% in studies of 5-year follow-up. The same review found that while the majority of BCC recurrences occur within 3 years following treatment, 18% appear between the 5th and 10th year, irrespective of treatment modality. The review concluded that lifetime follow-up of patients who have been treated for BCC is necessary.

One observational study found that UK dermatologists vary in terms of follow-up of patients treated for facial BCC. This study also found that dermatologists do not follow up all patients treated for BCC since clinics are too full, yet 92% of dermatologists reported follow-up of all patients with Gorlin's syndrome.

One observational study found the overall recurrence rate of BCC to be 5.1% and concluded that complete excision is key to surgical control, with no need for routine follow-up of patients where the BCC has been completely excised.

One observational study found that the interval between primary and recurrent BCC ranged from 2 to 12 years, with no definite correlation according to histological type of BCC. The authors concluded that all patients with excised primary BCC should be followed up for at least 3 years.

Squamous cell carcinoma

The BAD guidelines strongly recommend that self-examination is an important aspect of continued care and these recommendations are supported by a review of the current evidence.

One systematic review found that the local recurrence rates in patients with SCC range from 1.3% to 10%, across the different treatment modalities. Of those SCCs that recur, 58% do so within the first year of follow-up and 95% do so within the first 5 years of follow-up. The metastatic rate of primary SCC on sun-exposed sites ranges from 2.3% to 5.2%. The maximum period of follow-up was five years. Of those SCCs that metastasise, 69% do so within 1 year of follow-up and 96% do so within 5 years of follow-up. The review concluded that patients with SCC should have lifetime follow-up, in order to detect recurrence, metastasis and new primary skin cancers.

One observational study found the mean duration between excision and metastasis to be 10.3 months. The rate of metastasis was 2% overall and the authors suggested that follow-up of patients be maintained for at least 2 years after treatment.

Melanoma

All patients who have a diagnosis of invasive MM are at risk of recurrent disease and therefore doctor- or nurse-based follow-up is worthwhile. Although the risk can be predicted by a variety of independent risk factors, such as sex, ulceration and site, the single most commonly used predictor is the Breslow thickness. An inverse relationship is recognised between Breslow thickness and disease-free interval. There is, however, increasing evidence that the results from SNB are a better predictor of survival. SNB is an invasive procedure with potential morbidity; decisions to undertake SNB should only be made after careful consideration and only in the specific circumstances set out in the 'Initial investigation, diagnosis, staging and management' chapter.

One observational study found that 21.8% of patients with AJCC stage I MM relapsed. The authors concluded that only clinical examination is cost-effective in the detection of metastases and recommended that follow-up should be undertaken three times a year.

One observational study found that 20% of patients diagnosed with stage I MM developed recurrence. Doctor-diagnosed nodal recurrences were smaller and were associated with fewer histologically positive nodes than recurrences that were detected by patients. However, subsequent survival was identical in patients with recurrences detected by doctors and patients who detected recurrences themselves. Anxiety prior to clinic visits was reported by 54% of patients, whereas follow-up was considered worthwhile by 95% of patients.

Observational study evidence suggests that between 47% and 72% of recurrent MMs are detected by patients, and between 26% and 28% of recurrent MMs are detected by doctors.

Evidence from clinical guidelines based upon a systematic review concluded that follow-up of patients with MM should include clinical examination for a finite period and self-surveillance by patients throughout life.

Educating patients for self-examination

In the patient survey commissioned for this guidance, patients were happy to check themselves for skin cancer having received training, although some would prefer professional follow-up because of difficulty accessing certain areas such as the head and back. With respect to hospital follow-up, patients expressed a wish that follow-up be undertaken by the same person on subsequent occasions, preferably a consultant.

One RCT compared nurse education for self-performed skin examination plus provision of skin photographs with nurse education and provision of a standard brochure in patients with five or more atypical naevi, with or without a history of melanoma. The mean group scores for knowledge, awareness and confidence increased significantly in both groups at immediate follow-up, but there were no significant differences in scores between the photography group and the brochure group.

The RCT described above reported further follow-up at 4 months, and found that the teaching intervention with the photo book demonstrated a significantly greater increase in the number of patients reporting self-examination, compared to the group that received teaching and a standard brochure.

One systematic review found melanoma lesions detected by physicians to be thinner than those detected by patients. Elderly men had lower rates of self-examination and the authors recommended that physicians perform skin examination in these patients. The authors reported that the effect of promoting self-examination cannot be distinguished from that of routine screening in patients seeing the physician for unrelated reasons.

D. Measurement

Structure

- Network-wide guidelines for follow-up of patients by skin cancer type and stage.
- Availability of PET scanning for patients with suspected recurrent disease, when clinical doubt remains after other forms of imaging. PET is not routinely recommended for follow-up.

Process

- Audit of adherence to follow-up protocols.
- Assessment of patient attendance for follow-up.

Outcome

- Stage at diagnosis of recurrence or of metachronous cancers.
- Survival rates in patients with recurrent disease.
- Patient acceptability of either self- or clinic-based follow-up.

E. Resource implications

A resource implication of the recommendations for follow-up will relate to staff time needed to deliver training in self-surveillance to patients with low risk of recurrence of BCC or SCC. Staff time has been included in the estimates for additional staffing that have been detailed in the 'Organisation of skin cancer services' chapter. However, this investment is likely to be offset, in part, by capacity released as a result of discharging from long term follow-up those patients who have the capacity to self-monitor. This will become increasingly necessary as a result of increasing incidence.

The written and photographic information that has been produced by the Wessex Cancer Trust is widely used. The Wessex Cancer Trust is a charity and produced seven new cancer leaflets a year in 2004/05 (not all relating to skin cancer) at a cost of £12,414. Each leaflet costs an NHS trust 10p.

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Follow-up

BCC and SCC

The economic implications of this section have been included in the above, and are reported in the 'Organisation of skin cancer services' chapter in terms of the additional staff required to support the guidance.

Melanoma

The economic implications of this section have been included in the above, and in terms of the additional staff required to support the guidance are reported in the 'Organisation of skin cancer services' chapter.

F. Research priorities

- There is a need for well-designed ethics-committee-approved clinical trials of different follow-up methods.

5

Management of special groups

Introduction

Patients who are immunocompromised or who have a genetic predisposition are at increased risk of developing skin cancers. They are likely to develop precancerous lesions and cancers at a younger age and to develop multiple primaries. These patients and others with rare skin tumours (Appendix 1) may need more investigations, more intensive, earlier follow-up and specific, supportive care and information. Another group with special additional needs are children and young people with 'adult-type' skin cancers.

Genetic predisposition

There are a number of genetic conditions associated with the development of multiple skin cancers earlier in life than in the general population. The most common are described below.

The commonest genetic condition that predisposes to BCC is the basal cell naevus syndrome (Gorlin's syndrome), which is estimated to occur in 1 in 57,000 of the population. This is inherited as an autosomal dominant condition with a high spontaneous mutation rate. Affected individuals often have bony anomalies and dental cysts. In adult life they are at increased risk of BCC although BCCs can develop at very much younger ages. This risk is increased by exposure to irradiation, which must therefore be avoided. Sun avoidance throughout life should be promoted to prevent skin cancer.

Xeroderma pigmentosum (XP) is a rare autosomal recessive disorder. The estimated frequency is one case per 250,000 population in the United States and Europe. Within the first few years of life, BCC, SCC, sarcomas and MM start to develop if sun protection does not occur.

Genetic predisposition to MM may also occur, with approximately 1–5% of patients with MM having a family history. Rare high-risk genes occur that are inherited as autosomal dominants, and these may manifest as multiple primary tumours in an individual and/or clustering in families. Most families with these genes in the UK are at increased risk of MM alone. In other countries there also appears to be an increased risk of pancreatic cancer.

The incidence of MM in the UK is around 10 per 100,000 per annum. Allowing for 80% survival and a mean age of 51 at diagnosis, an estimated population prevalence is around 1 in 10,000. The majority of these will have high-penetrance genes resulting in a lifetime risk of developing MM of between 60% and 80%.

In the general UK population, individuals with multiple moles (the atypical mole syndrome [AMS]) are at increased risk of MM and this is thought to be genetic, probably due to low-penetrance susceptibility genes. The phenotype is, however, common and patients with the AMS require education about prevention, both primary (sun avoidance) and secondary (signs and symptoms). Patients with AMS have a relative risk of MM of around 10 compared with those who have very few moles. The lifetime risk of MM in the UK is approximately 1 in 150; patients with AMS have an estimated 1 in 20 lifetime risk compared with a person with an average number of moles. Their risk is lower when compared, for example, with those with XP, but as 2% of the general population have the AMS these patients 'explain' a significant proportion of the disease.

Organ transplant patients

There is epidemiological evidence that patients who have had an organ transplant are at high risk of developing all types of skin cancers as a result of long-term immunosuppression. The risk increases with time following the transplant and is higher in older patients and white-skinned people who have had excessive sun exposure. These patients are especially at risk of developing SCC of the skin and often have multiple and fast-growing tumours, which may pose difficulties in their management. As organ transplant recipients live longer, so the prevalence of skin tumours with metastases in this population will increase.

Skin lymphomas

Skin lymphomas represent a special group because of their rarity and complexity in diagnosis and because of service overlap with haematology. There are two key national clinical guidelines for cutaneous lymphoma: the Royal College of Pathologists minimum dataset for lymphoma⁵⁶ and the joint BAD/UK Skin Lymphoma Group *Guidelines for the management of primary cutaneous T-cell lymphoma (CTCL)*.⁵⁷ The NICE guidance *Improving outcomes in haematological cancer*⁵⁸ is also relevant, though not specifically concerned with primary cutaneous lymphoma.

There are approximately 300 new cases of cutaneous lymphoma annually in the UK. Although all cutaneous lymphomas are malignant, the majority are of low-grade biological type and associated with long survival, so accordingly the prevalence is relatively high. Unlike other lymphoma patients, most individuals with skin lymphomas require directed treatment of their skin and not systemic chemotherapy, which is only needed for patients with advanced disease. The histological diagnosis of skin lymphoma is a specialised field and has been included in the National Pathology and Dermatology Specialised Services.

A primary cutaneous lymphoma is defined as a lymphoma arising within the skin without evidence of systematic spread at presentation. Approximately 30% of cases are B-cell and the remainder are T-cell (CTCL), with a few NK-cell lymphomas. The commonest type of cutaneous T-cell lymphoma is mycosis fungoides, which accounts for approximately 70% of all cases of CTCL. Prognosis in CTCL varies widely depending on subset and stage: patients with lymphomatoid papulosis or stage 1a mycosis fungoides have a virtually normal life expectancy whereas patients with CD30-negative large cell lymphoma, or Sézary syndrome, have a median survival of less than 5 years. Clinical and pathological expertise is therefore crucial for making the correct diagnosis and thus deciding the appropriate therapy. In addition, molecular analysis of tumour tissue also provides valuable diagnostic information, and molecular analysis of blood and lymph tissue can provide valuable prognostic information in patients with mycosis fungoides. Similar principles apply to other types of cutaneous lymphoma. Whereas patients with marginal zone B-cell lymphoma have a 5-year survival of almost 100%, those with blastic NK-cell lymphoma have a 5-year survival of less than 20%. Thus all

⁵⁶ Royal College of Pathologists. *Standards and minimum datasets for reporting cancers*. Available from: www.rcpath.org

⁵⁷ British Association of Dermatologists (2003) *Guidelines for the management of primary cutaneous T-cell lymphomas*. Available from: www.bad.org.uk/healthcare/guidelines

⁵⁸ National Institute for Clinical Excellence (2003) *Improving outcomes in haematological cancer*. Available from: www.nice.org.uk

patients with cutaneous lymphoma should have diagnostic biopsies for histology, immunophenotyping and molecular studies, and the results should be correlated with the clinical presentation.

As there are so few cases of cutaneous lymphoma per year (especially when broken down into sub-type), few specialists have experience or expertise in this area and specialised facilities, such as photopheresis for the treatment of erythrodermic CTCL and total skin electron beam (TSEB) radiotherapy, are available in only a handful of centres in the UK. Management of patients with rare types of cutaneous lymphoma and patients with more advanced disease should therefore take place in a supraregional centre.

Skin sarcomas

It is entirely appropriate for cutaneous sarcomas to be reviewed by the SSMDT and where appropriate patients should be referred to the sarcoma MDT.

Kaposi's sarcoma

Kaposi's sarcoma (KS) is an angioproliferative disease, which primarily affects the skin but can progress to involve the lymphatic system, the lungs and the gastrointestinal tract; rarely bone involvement can occur. Classical KS is a slowly progressive disease affecting Ashkenazi Jews and others of Mediterranean origin. Classical KS affects mainly the lower limbs, although dissemination can occur, particularly in association with immunosuppression. Epidemic KS is related to immunosuppression and is most commonly seen in HIV-infected patients, but is now increasingly reported in immunosuppressed post-transplant patients. One-third of patients with classical KS require no treatment, but for those patients who require intervention, the same spectrum of treatment modalities as are used in epidemic KS are also active in classical KS.

In the early days of the AIDS epidemic up to 40% of patients either presented with KS as their AIDS-defining illness or developed it during the course of the illness. Since the introduction of highly active antiretroviral therapy (HAART) at an early stage after diagnosis of HIV infection, the incidence of Kaposi's sarcoma has dropped dramatically to about 10% of the incidence seen 15 years ago. In addition to reducing the incidence of KS, HAART also has a therapeutic effect on established KS, both causing regression of disease and prolonging the disease-free interval.

The majority of cases diagnosed in the UK today present with advanced disease and previously undiagnosed HIV infection. A recent telephone survey of clinical oncology departments in London suggests that there were fewer than 50 cases treated in London during the past 12 months.

Local therapies including cryotherapy, radiotherapy and topical treatments are effective for treating patients with early skin lesions. Many patients presenting with KS will respond to HAART and require no other intervention. Unsightly lesions on the face or other exposed areas may be excised or may respond well to short courses of radiotherapy. More extensive limb involvement responds well to wide-field irradiation. When the disease is progressing rapidly in spite of HAART or when there is visceral involvement, systemic treatment with cytotoxic chemotherapy is indicated.

Children

The National Institute for Health and Clinical Excellence has published service guidance for *Improving outcomes in children and young people with cancer*.⁵⁹ This guidance does not address specifically the occurrence in children or young people of skin cancers that are more commonly seen in adulthood. Although skin cancers are rare in children and young people, the clinical features are identical to those occurring in adults and the recommended treatment is similar to that for skin cancers occurring in adults. However, patients in these groups, and their carers, are likely to have complex physical and psychosocial needs. In addition to high-quality management for their skin cancer they may need additional supportive care tailored to the needs of children and young people with cancer.

⁵⁹ National Institute for Health and Clinical Excellence (2005) *Improving outcomes in children and young people with cancer*. Available from: www.nice.org.uk

A. Recommendations

Generic recommendations for patients with uncommon risk factors or rare cancers

Specialised services commissioners, together with their cancer network(s), should undertake a needs assessment for these special groups of patients, plan the provision of appropriate specialist care and put in place the necessary commissioning arrangements.

Network-wide protocols should be developed that describe the pathways of care for these special groups of skin cancer patients.

Commissioners should receive results of audits of the care of these special groups.

Commissioning for national specialised pathology services for rare skin tumours should be reviewed by the specialised services commissioners.

There should be good liaison between the SSMDT and the haemato-oncology MDT. Specifically, systemic/nodal lymphomas presenting in the skin should have haemato-oncology MDT review. Likewise, primary cutaneous lymphoma presenting to, for example, haematologists should receive SSMDT review.

There should be a close liaison between the SSMDT and the soft tissue sarcoma MDT. It is appropriate for many cutaneous sarcomas to be considered by the SSMDT but some should also be discussed at the sarcoma MDT, especially those that penetrate the superficial fascia or require chemotherapy.

Information provision for patients in these special groups should be tailored to their specific needs and contain information on their condition and relevant patient support groups. Links should be made to national support groups, to assure the quality of information (see chapter on 'Patient-centred care').

Treatment strategies for individual patients should be made and developed in the context of MDT meetings at which all relevant clinical specialists, including a CNS who knows the patient, should be present.

All patients with a high risk of developing skin cancer should be counselled effectively by a dermatologist or a CNS about sun protection before they develop any skin lesions, and should have annual checks carried out thereafter.

All patients in high-risk groups with precancerous skin lesions (e.g. multiple warty lesions and/or AK) should be referred early to a dermatologist for assessment, active treatment and follow-up.

Once patients at high risk start to develop skin lesions they should be offered at least 6-monthly follow-up.

Genetic predisposition

Patients with evidence of genetic predisposition and their families should be offered referral to the clinical genetics services or a specialist dermatology service. The criteria for referral for families with MM are:

- three or more family members with MM, or
- two first-degree relatives with MM, or
- two relatives with MM, one of whom had multiple primaries.

Patients with familial MM, Gorlin's syndrome or XP should be reviewed by SSMDTs and be managed by dermatologists and surgeons who have expertise in these conditions.

Patients with Gorlin's syndrome should not be treated with radiotherapy.

Transplant patients

Transplant patients who have precancerous skin lesions or who have developed a skin cancer should be seen in a dedicated 'transplant patient skin clinic', either in the transplant centre or in a hospital closer to the patient's home, according to the choice of the patient.

Close links should be established between the transplant centre, local physician and dermatologist for the management of transplant patients postoperatively.

Dermatologists managing transplant recipients with multiple and/or recurrent skin cancers need to liaise with the transplant team regarding reduction of immunosuppression and the use of systemic retinoids in order to reduce the risk of invasive disease.

Cutaneous lymphoma

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All patients should be seen by and managed by the SSMDT, which should include a dermatopathologist with expertise in cutaneous lymphoma (NICE guidance on *Improving outcomes in haematological cancers*⁶⁰). Close liaison should be maintained with a haemato-oncopathologist, as appropriate. Cases of possible systemic haematological malignancy involving the skin should be referred to the appropriate haematological malignancy MDT.

LSMDTs should be involved once the diagnosis and staging has been confirmed by the SSMDT.

Patients with lymphomatoid papulosis or stage Ia mycosis fungoides could be managed locally by the LSMDT after diagnosis.

Patients with rare types of cutaneous lymphoma and those with later stages of mycosis fungoides (stage IIb or above) should be seen in and have easy access to supranetwork centres for specialist advice and access to treatment facilities. There should be a small number of such centres nationally and they would not be present in every cancer network.

These supraregional services should be commissioned under regional specialised commissioning so that the expertise can be concentrated where the treatment facilities are available and so that tertiary referral centres can undertake clinical studies based on a meaningful number of patients.

All lymphoma patients should undergo diagnostic biopsies for histology, immunophenotyping and molecular studies, and this should be correlated with clinical presentation for accurate diagnosis and prognosis.

The SSMDT should have access to specialist laboratory testing of tumour tissue and blood for immunophenotyping, molecular analysis and blood viral serology.

Initial staging imaging is required in all patients with the exception of stage 1 mycosis fungoides and lymphomatoid papulosis.

⁶⁰ National Institute for Clinical Excellence (2003) *Improving outcomes in haematological cancer*. Available from: www.nice.org.uk

The SSMDT should have access to bone marrow aspirate and trephine biopsies for complete staging of all patients with B- and NK-cell lymphomas and for patients with CTCL variants and late stages of mycosis fungoides (stage IIb or above).

The World Health Organization (WHO)–EORTC primary cutaneous lymphoma classification should be used to classify primary cutaneous lymphomas.

Chemotherapy should be reserved for patients with advanced disease as it may have a detrimental effect on those with early disease.

Skin sarcomas

Skin cancer MDTs should liaise with sarcoma MDTs in the management of patients with cutaneous sarcomas. As stated in the section on SSMDTs, it is essential for all cutaneous sarcomas to receive specialist histopathology review.⁶¹

Sarcomas needing SSMDT review include all those involving the dermis and subcutaneous fat above the superficial fascia. It is appropriate for small/superficial cutaneous sarcomas to be dealt with by the SSMDT.

It is essential that there is close liaison between the SSMDT and sarcoma MDTs. This is particularly important for patients whose sarcomas are large or penetrate the superficial fascia or are of a histological type requiring chemotherapy (e.g. rhabdomyosarcoma, Ewing's sarcoma).

Patients with KS should be referred to experts in the management of this tumour.

Children and young people

All children and young people diagnosed with skin cancer should be managed within the context of an MDT, which will include a dermatologist expert in skin malignancies and have access to specialist children and young people cancer support services and inpatient facilities at network level (see NICE service guidance *Improving outcomes in children and young people with cancer*⁶²).

⁶¹ National Institute for Health and Clinical Excellence (Publication due March 2006) *Improving outcomes in people with sarcoma*. Available from: www.nice.org.uk

⁶² National Institute for Health and Clinical Excellence (2005) *Improving outcomes in children and young people with cancer*. Available from: www.nice.org.uk

Children and young people with skin cancer should be given the opportunity of entering into NCRI-approved clinical trials, as recommended in the NICE service guidance *Improving outcomes in children and young people with cancer*.⁶³

B. Anticipated benefits

A structured and coordinated approach to these groups of patients with special needs will allow issues such as prevention, surveillance, access to services, quality of life and comorbidities to be better managed.

Appropriate treatment for these patients can be expected to improve both short- and long-term outcomes.

Patients and carers who are offered full information about all potential treatment options and their anticipated effects can contribute better to participative decision-making.

Where children and young people meet the eligibility criteria for NCRI-approved clinical trials, their participation will add to the evidence base.

Involving specialists from a range of disciplines at an early stage allows all aspects of the patient's condition and situation to be considered in decision-making.

C. Evidence

Genetic predisposition

A meta-analysis has shown that the risk of developing a melanoma is much higher in people with more than 100 common naevi or five atypical naevi.

A consensus statement from the Melanoma Genetics Consortium reports that while less than 1–2% of melanoma cases are thought to be attributable to genetic mutations, people with one or more affected first-degree relatives have an increased risk of developing a melanoma and those with multiple affected family members have a much greater risk. There is evidence that suggests that, of the melanoma types, superficial spreading melanoma shows the highest familial risk, and two case control studies have found an increased risk of melanoma associated with the presence of numerous atypical naevi.

⁶³ National Institute for Health and Clinical Excellence (2005) *Improving outcomes in children and young people with cancer*. Available from: www.nice.org.uk

Observational studies that address the risk of melanoma arising from congenital melanocytic naevi (CMN) report that children with large CMN are at greatly increased risk of cutaneous and non-cutaneous melanoma, warranting continuous surveillance. Larger CMN pose a greater risk than smaller lesions. Small CMN (< 10 cm in largest diameter) are considered precursors to epidermal melanoma which largely occurs after puberty. Giant nevi (> 20 cm in largest diameter) pose a risk for dermal melanoma predominantly in pre-pubescent children, although these naevi may also produce epidermal melanomas after puberty.

Lymphoma

Clinical guidelines and expert reviews support the opinion that patients with cutaneous lymphoma should be managed by an MDT.

One RCT demonstrated that early intervention in mycosis fungoides using multi-agent chemotherapy does not improve survival but does increase morbidity.

Clinical guideline evidence supports avoidance of toxic or aggressive therapies in the treatment of patients with early-stage disease. Skin-directed treatment (topical therapy, superficial radiotherapy and phototherapy) has been shown to achieve long periods of remission and is the most appropriate therapy in early-stage disease.

Five-year survival varies according to lymphoma type and is estimated to be 70–90% in patients with mycosis fungoides and 10–50% in patients with Sézary syndrome. The quality of life of patients with cutaneous lymphoma may be severely affected over many years.

Kaposi's sarcoma

Two expert reviews found that HAART is associated with a dramatic decrease in the incidence of KS and can bring about tumour regression. One observational study found that HAART is associated with prolonged disease control in patients with KS.

Expert review evidence reports that local therapies including cryotherapy, radiotherapy and topical treatments are effective for treating patients with early skin lesions and that, in general, systemic chemotherapy for KS is a treatment option for patients with widespread, symptomatic disease.

Gorlin's syndrome

Two expert reviews report that people with Gorlin's syndrome have an increased risk of developing BCCs, with onset as early as 2 years but usually from puberty to 35 years of age. This risk increases with exposure to sunlight. Patients with the syndrome may develop thousands of BCCs, ranging in size from 1 mm to 10 mm in diameter and most often involving the face, back and chest. Topical body application of tretinoin or fluorouracil can control lesions. The use of oral retinoids is debated. PDT can give a high rate of tumour response. There is evidence that radiotherapy should not be used in patients with Gorlin's syndrome.

Transplant patients

One RCT comparing two doses of oral acitretin in renal transplant recipients found that oral acitretin reduces the number of actinic keratoses, although the drug was poorly tolerated by patients.

Evidence-based guidelines produced by the Evidence Based Practice Group, Expert Group on Renal Transplantation (2002) recommend that patients should be educated about primary prevention of skin cancer and that transplant recipients with pre-malignant skin lesions should be referred early to a dermatologist. Secondary prevention for recipients should include close follow-up by a dermatologist and treatments for skin cancer including topical retinoids, reduction of immunosuppression whenever possible and, for multiple or recurrent skin cancer, systemic retinoids.

Evidence from observational and expert review studies suggests that transplant patients are at increased risk of developing skin cancer. SCC is the most common post-transplantation skin cancer, occurring earlier and growing more quickly than in the general population. The risk appears to be greater where immunosuppression is intense or maintained for a long time.

Observational and clinical guideline evidence suggests that chemoprophylaxis with systemic retinoids may reduce the incidence of skin cancer.

Observational study evidence suggests that reducing or stopping immunotherapy can be an option for managing skin cancer only after careful consideration of the risk of organ rejection with the patient's transplant physician.

A survey of transplant physicians reported that closely integrated and well-coordinated specialist clinics for dermatological management of transplant patients are highly effective.

Children

The evidence base underpinning service configuration for the support of children and young people with cancer has been reviewed in the NICE Cancer Service Guidance *Improving outcomes in children and young people with cancer*.

Children and adolescents in clinical trials

A systematic review that investigated patient outcomes between participants and non-participants (including children and adults) in controlled trials found little evidence for better outcomes or greater risks through participation in trials.

Two observational studies indicate that adolescents do not have the same access to trials as adults. An expert review found little generalisable evidence to suggest that trial participation directly improves outcomes.

D. Measurement

Structure

- Network-wide written protocols covering the management of patients within these groups.
- Systems to enable quick access to MDT management/special clinics for patients in these groups.
- Appropriate information on the issues related to these high-risk groups and on facilities and access to staff for patients and their carers.
- Availability of written or other appropriate information for patients in these groups about their condition, proposed interventions, members of the MDT and their roles, and hospital and support services.

Process

- Audit of adherence to protocols in the management of these patients.
- Evidence of agreement between various MDTs regarding protocols in relationship to the various skin cancers; this may include skin cancer MDTs, soft tissue sarcoma MDTs, head and neck MDTs and haematology MDTs.
- Evidence that patients have been given written information describing the procedures they undergo, and that this information covers the resultant risks as well as anticipated benefits.
- Surveys of patients' and carers' views on their information and support needs, as well as their experience of services.

Outcome

- Proportion of patients recruited to clinical trials.
- Quality of care and outcomes for all patients with skin cancer.

E. Resource implications

Generic recommendations for patients with uncommon risk factors or rare cancers

These recommendations will have an impact on MDTs and staffing levels, included in the additional staff required as a result of the guidance, as detailed in the chapter on 'Organisation of skin cancer services'.

The improved coordination of care and treatment of these patients may lead to cost savings that it is not possible to calculate.

Genetic predisposition

This recommendation concerns rare conditions including familial MM, Gorlin's syndrome and xeroderma pigmentosum (XP). In some networks there may be capacity within existing genetics services. This will require further investigation by local commissioners.

Transplant patients

It is likely that there will be a need for a transplant patient skin clinic to be established in each of the existing 28 transplant units in England and Wales. In addition, the guidance makes provision for patients who wish to attend a clinic closer to home. For the purposes of the resource implications, it is estimated that there would be one such clinic established in each network; this will vary according to need. The employment cost for the staff involved is likely to be between £4370 for one monthly clinic per network and £17,480 for a weekly clinic per network. Frequency of meetings would vary according to patient activity. The cost implications relating to special patient groups will vary between networks.

Cutaneous lymphoma

There will be resource implications connected with the establishment of supranetwork centres for advice and treatment for patients with cutaneous lymphoma. There may be a need to establish a specific SSMDT for these patients in supranetwork centres or supraregional units, when these are commissioned. The costs relating to such teams would require further investigation by the commissioners.

Skin sarcomas

The economic implications of this section have been included in terms of the additional staff required to support the guidance, reported in the 'Organisation of skin cancer services' chapter.

Children and young people

The economic implications of this section have been included in the 'Organisation of skin cancer services' chapter.

F. Research priorities

- Advances in the research evidence base on disease processes and the management of these patients are critical.
- Research focused on chemotherapeutic agents and/or biological response modifiers should continue and include these patients where appropriate.
- There is a requirement for more research into the management of Gorlin's syndrome and familial MM.

- Cutaneous lymphoma is so rare that there are few data to inform treatment. UK treatment programmes should be organised to offer patients participation in national or European clinical trials. Registration of patients into a national database should be encouraged.
- Research should continue to evaluate new agents for the treatment of cutaneous lymphoma.
- A programme of autologous and/or allogeneic transplantation for CTCL should only be undertaken by designated centres in the UK, in a research setting. The treatment programme must be carried out maintaining close liaison between the MDT for cutaneous lymphoma and the transplant centre.
- Anti-angiogenic agents should be further evaluated for the treatment of KS.
- There is a requirement for more research in transplant-related skin malignancy including prevention, epidemiology, pathogenesis and treatment.

Appendix 1

List of rare skin tumours

A1

Epidermal and appendage tumours

Apocrine carcinoma.

Hidradenocarcinoma.

Eccrine porocarcinoma.

Sebaceous carcinoma.

Tumours associated with Muir–Torre syndrome.

Eccrine epithelioma (syringoid carcinoma).

Microcystic adnexal carcinoma.

Primary adenoid cystic carcinoma.

Primary mucoepidermoid carcinoma.

Primary mucinous carcinoma.

Digital papillary adenocarcinoma.

Malignant cylindroma.

Malignant spiradenoma (spiradenocarcinoma).

Malignant pilar tumour.

Malignant pilomatrixoma.

Neuroendocrine carcinoma (Merkel cell tumour/trabecular carcinoma).

Dermal and subcutaneous tumours

*Improving Outcomes for
People with Skin Tumours
including Melanoma*

Appendix 1

Atypical fibroxanthoma (AFX) (superficial malignant fibrous histiocytoma, superficial sarcoma not otherwise specified).

Dermatofibrosarcoma protuberans (DFSP).

Leiomyosarcoma.

Angiosarcoma.

Kaposi's sarcoma.

Haemangioendothelioma.

Epithelioid sarcoma.

Primary cutaneous rhabdomyosarcoma.

Cutaneous malignant nerve sheath tumours (including cutaneous neurofibrosarcoma and malignant Schwannoma).

A1

Appendix 2

Scope of the guidance

Scope

1. Guidance title

Guidance on Cancer Services: *Improving outcomes for people with skin tumours including melanoma.*

Short title

Skin tumours.

2. Background

- a) The National Institute for Health and Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Cancer to develop service guidance on skin tumours for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and Welsh Assembly Government (see page 131). The guidance will provide recommendations for service provision that are based on the best available evidence.
- b) The Institute's service guidance will support the implementation of the National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The guidance will support current national initiatives outlined in the *NHS Cancer Plan*, the Calman–Hine report, the Cameron report, the 'Manual of Cancer Service Standards for England' and the 'All Wales Minimum Standards for Cancer Services'.

- c) The guidance will also refer to other NICE service guidance documents currently under development, including Referral Guidelines for Suspected Cancer Supportive and Palliative Care for People with Cancer, Service Guidance for Improving Outcomes in Child and Adolescent Cancer and Improving Outcomes in Haematological Cancers. The guidance will also refer to national standards as appropriate (for example, waiting times). Cross reference will be made to these and other documents as appropriate.

3. Clinical need for the guidance

- a) Skin cancers constitute the most common group of cancers in the UK. There are approximately 65,000 new cases registered in England and Wales each year, but it is generally agreed that the actual number is considerably greater. The incidence of all types of skin cancer is steadily increasing mainly as a result of social changes including increased sun exposure.
- b) Malignant melanoma, although overall an uncommon tumour, is the third most common tumour in the 15 to 39 age group, and a significant cause of cancer mortality in this group. There are approximately 5200 new cases registered in England and Wales and approximately 1500 deaths each year, with a 5-year survival of 42% in men and 54% in women (ONS, Cancer Research UK).
- c) Non-melanoma skin cancers, especially basal and squamous carcinomas, are most common in older age groups. These are rarely fatal – there are about 450 deaths per year, but they can result in considerable morbidity. Many patients develop multiple tumours, presenting either at the same time or subsequently.
- d) Primary cutaneous lymphomas are quite uncommon, with around 100 cases per year, but generate particular issues in their overall management.

4. The guidance

- a) The guideline development process is described in detail in three booklets that are available from the NICE website (see 'Further information'). *The Guideline Development Process – Information for Stakeholders* describes how organisations can become involved.

- b) This document is the scope. It defines exactly what this piece of service guidance will (and will not) examine, and what the developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see page 131).
- c) The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

- a) Adults with malignant tumours of the skin (basal cell carcinoma, squamous cell carcinoma, malignant melanoma and other rare primary tumours).
- b) Adults with primary cutaneous lymphomas.
- c) Adults with skin tumours arising in immuno-compromised patients.
- d) Children and young people in their late teens and early twenties presenting with skin tumours typical of the adult group, whose management does not generally require specialist paediatric oncology services.
- e) Adults and children with precancerous skin lesions such as actinic keratoses, Bowen's and lentigo maligna, including the specific needs of people with genetic disorders.

4.1.2 Groups that will not be covered

- a) Adults and children with benign skin tumours.
- b) Adults and children with cutaneous metastases from tumours at other primary sites.

4.2 Healthcare setting and services

4.2.1 Healthcare settings and services that will be covered

- a) Primary care, including diagnosis, treatment and follow-up.
- b) Secondary care, including the role of skin cancer networks and multidisciplinary teams.
- c) Tertiary care in cancer centres, specialist dermatology centres and specialist plastic surgery units.

4.2.2 Healthcare settings and services that will not be covered

- a) Primary prevention and education.

4.3 Key areas of clinical management

The following key areas of clinical management will be included, because they have direct implications for service delivery.

- a) Services for Diagnosis and Staging (excluding those being addressed as part of the updated referral guidelines) including:
- General practitioners and other members of the primary care team
 - Dermatology departments
 - Plastic surgery units
 - Pathology departments
 - Radiology and nuclear medicine departments
 - Telemedicine

In addition, the guidance will address the important issue of data collection and registration of skin tumours.

- b) Treatment services, to include treatment in the following settings.
- Primary care – surgery, cryotherapy, topical chemotherapy.
 - Dermatology centres – surgery, Mohs surgery, cryotherapy, photodynamic therapy, topical chemotherapy, laser therapy and immunotherapy.
 - Plastic surgery units, including oculoplastic surgery.
 - Cancer centres – radiotherapy, chemotherapy and immunotherapy.
 - Other specialised units such as maxillofacial surgery, ENT, and genetics.
- c) Multi-professional working and service integration across sectors.
- d) Follow-up.

- e) Supportive care of skin cancer patients, including the role of specialist nurses, rehabilitation, physiotherapy, psychological/psychiatric services, occupational therapy, prosthetics and skin camouflage (in those areas that have not already been covered by the Supportive and Palliative Care for People with Cancer guidance).
- f) Palliative care (in those areas that have not already been covered by the Supportive and Palliative Care for People with Cancer guidance).
- g) Information resources for patients, carers and family members.
- h) Health service research and clinical trials on service delivery.

4.4 Audit support within the guidance

The guidance will include key criteria for audit, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, particularly its impact upon practice and outcomes for adults with skin cancer.

4.5 Status

4.5.1 Scope

This is the final version of the scope.

4.5.2 Guidance

The development of the service guidance recommendations will begin in October 2003.

5. Further information

Information on the guideline development process is provided in:

- The Guideline Development Process – Information for the Public and the NHS
- The Guideline Development Process – Information for Stakeholders
- The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups.

These booklets are available as PDF files from the NICE website (www.nice.org.uk). Information of the progress of the guideline will also be available from the website.

The Department of Health and Welsh Assembly Government asked the Institute:

‘To prepare service guidance for the NHS in England and Wales for cancer of the skin. This would form part of the “Improving cancer outcomes” series with NICE expected, as previously, to involve DH and NAW closely in the development of the guidance. In particular, DH and NAW should be alerted at an early stage to any issues in the developing guidance, which are likely to lead to significant changes in the current service provision.’



Appendix 3

Economic implications of the guidance

Executive summary

A summary of the economic consequences of the recommendations of the Guidance on Cancer Services: *Improving outcomes for people with skin tumours including melanoma* in England and Wales are set out in this section. The analysis focuses on those aspects of the key recommendations that are likely to be of greatest consequence in terms of cost, the most significant of which will be in respect of additional staffing.

There is uncertainty around the estimates presented and there will be variation between cancer networks. Sensitivity analyses were conducted to account for uncertainty in the estimated costs. Further assessments will be needed at cancer network level and/or NHS trust level to determine the exact cost implications. Work is currently being carried out in the NHS in England, in connection with Payment by Results, to develop a better understanding of costs of treatment and care, and this may help these assessments in the future.

The summary of the economic implications is outlined in two tables. Table A1 presents service delivery options regarding clinicians working in the community and for multidisciplinary team (MDT) working, the resource implications of which will be dependent upon the level of existing services. Table A2 presents additional resource implications that apply across cancer networks.

A3

Table A1. Summary of service options and annual resource implications for cancer networks

		Estimate (£)	Range (£)	
Community clinicians	Service cost, inclusive of staff time and consumables	625,727	469,296	782,159
	GPwSI sessional rate	329,373	247,030	411,716
	Hospital practitioner sessional rate	196,773	147,580	245,966
MDT	For cancer networks with no MDTs, moving to low MDT provision	129,134	96,851	161,418
	For cancer networks with no MDTs, moving to high provision	258,268	193,701	322,835
	For cancer networks with partial MDTs, moving to low provision	49,888	37,416	62,360
	For cancer networks with partial MDTs, moving to high provision	105,662	79,246	132,077

A3

Table A2. Summary of annual cancer network level resource implications

		Range ¹ (£)	
Additional staff	MDT coordinators	44,470	88,941
	Skin cancer clinical nurse specialists (CNS)	142,330	177,913
	Consultants	555,284	555,284
Sub-total		742,085	822,138
Special groups ²	Transplant patients	4,370	17,480
Cancer registries	Set-up costs³	963	1,482
	Recurring costs	963	1,482
Total (range)		747,418	841,101

¹ Costs reflect low and high staffing requirement, rounded to the nearest £.

² Assuming one clinic per cancer network.

³ One-off cost and not added into annual total.

Clinicians working in the community

The guidance states that some patients with precancerous or low-risk BCCs may be diagnosed, treated and followed up by clinicians working in the community under the direction of an MDT. The need for community skin cancer clinics will vary according to the expertise available and ease of access to local hospital departments. Some cancer networks already have such services in place and it will be for local commissioners to decide whether to establish them where there is currently no such provision.

In the absence of cost-effectiveness evidence, a survey was conducted to inform the resource implications of the guidance. The costs include sessional rates paid to general practitioners with a special interest (GPwSI) in dermatology in the community and a more comprehensive service cost that includes GPwSI, nurse and administrator time and consumables. In addition, hospital practitioner sessional rates have been included (Table A1). The costs at a cancer network level for the service inclusive of GPwSI time, nursing time, administration and consumables is around £625,727 per network (\pm 25% range, £469,296 to £782,159). For a cancer network to deliver 30 sessions a week for 52 weeks of the year, the annual cost of those sessions, with a GP locum payment, would be around £329,373 (\pm 25% range, £247,030 to £411,716); at hospital practitioner rates the payment would be £196,773 (\pm 25% range £147,580 to £245,966). Thirty sessions in a network equates to 3.4 sessions per PCT or LHB. These cost scenarios have a high degree of uncertainty because they include an element of costs for patients that have conditions other than non-melanoma skin cancer (NMSC). It also needs emphasising that the costs have been presented for information purposes and it is for local commissioners to investigate whether a GPwSI service would enhance their existing services.

Multidisciplinary teams

The guidance recommends that cancer networks should establish two levels of multidisciplinary team – LSMDTs and SSMDTs. Skin cancer teams are currently established in some but not all cancer networks. It is estimated that 36% of all networks require at least one SSMDT. Fifty percent of networks require between three and six LSMDTs with a further 23% requiring a further two to four LSMDTs.

All costs in this section are based on the MDT meeting every 2 weeks. For those cancer networks currently without any skin cancer MDTs in place, the estimated annual opportunity costs for attending MDT meetings is estimated to be between £129,134 (\pm 25%, £96,851 to £161,418) and £258,268 (\pm 25%, £193,701 to £322,835).

For those cancer networks with partial MDT provision, the annual opportunity cost related to forming one SSMDT would be £49,888 (\pm 25%, £37,416 to £62,360) and £105,662 (\pm 25% range, £79,246 to £132,077) for four LSMDTs. The number of teams required per cancer network will vary in line with population; this will require investigation by local commissioners. There will be additional costs relating to the employment costs of an FTE MDT coordinator/data manager for each team of around £22,582 per year. It is anticipated that an additional two to four coordinators will be required per network with an employment cost of £44,470 to £88,941 per year.

Additional staffing and training

It is estimated that between £742,085 and £822,138 would be required per cancer network per year for the employment of additional staff to sustain the increased workload as a result of the guidance (Table A2). Not all this money will be new, as it is likely that the personnel will be existing staff who will train to fulfil such specialist posts through continuing professional development programmes. As with the costs associated with increased MDT provision, the cost consequence will not be immediate. There will be an additional training cost of between £24,570 and £98,280 in each of the 31 networks that currently do not have consultants with an expertise in performing Mohs surgery.

Special groups – transplant patients

Transplant patients are one of the groups that receive special consideration in the guidance. The guidance recommends that patients are managed by dedicated 'transplant patient skin clinics' either in the transplant centre or in a hospital closer to the patient's home. There are 28 existing transplant units in England and Wales. It is estimated that there would be at least one such clinic established in each cancer network; the exact number will vary according to patient need. The employment costs for the staff involved is likely to be between £4370 and £17,480 for one monthly clinic per cancer network. The frequency of meetings would vary according to the size of the transplant population. It should be noted that the cost implications relating to special patient groups will vary among cancer networks. Local commissioners need to be aware that treatment of transplant patients with tumours will become progressively more important with the increasing numbers of organ transplants being performed together with the recipients' life expectancy.

Cancer registries

The guidance recommended that at least two cancer registries should receive additional funding to undertake full registration of skin cancers. The additional costs associated with this recommendation for one registry are between £35,638 and £54,842 for staff training for the first year, with the same level of annual recurring costs dependent upon exactly how many additional staff are required. At the cancer network level this would be between £963 and £1482. Costs are based on Agenda for Change pay rates for 2005/06, Band 2–4, point 7 and point 12, plus 20% employment oncosts. In practice it might be that this is an overestimate. This cost is likely to decrease as registries become fully automated.

How this guidance manual was produced

This service guidance is intended to guide health organisations (Strategic Health Authorities, Primary Care Trusts, Local Health Boards, Cancer Networks and Trusts), their managers and lead clinicians in improving the effectiveness and efficiency of services for people with skin tumours including melanoma. The information and recommendations in the manual are based on reviews of the best available evidence on diagnosis, treatment and service delivery. This evidence is retrieved by information specialists and assessed by researchers within the National Collaborating Centre for Cancer (NCC-C) and the recommendations are the product of extensive discussion with the Guidance Development Group (GDG). A brief overview of the development process of the guidance is provided below.

The first stage in the development of the guidance was the production of a scope (Appendix 2), which defined in detail the patient population, the healthcare settings and services and key areas of clinical management that the guidance should cover. This was then subject to a 4-week consultation with registered stakeholders in line with NICE methodology. Following this a multidisciplinary GDG was formed, comprising clinicians representing the main stakeholder organisations and representatives from relevant patient organisations and charities (Appendix 5.2). The GDG was convened by the NCC-C and chaired by Dr Julia Verne in close association with the Clinical Lead, Dr Dafydd Roberts. All GDG members made and updated any declarations of interest. The Group met on a monthly basis during development of the guidance and NCC-C staff provided methodological support and leadership for the development.

During the development phase of the guidance the GDG identified areas where there was a requirement for expert input on particular specialist topic areas. These topics were addressed by the production of a position paper by a recognised expert who had been identified via the relevant registered stakeholder organisation. All relevant expert positions papers are presented in the Evidence Review.

A4

The identification and retrieval of evidence to support the recommendations in the guidance is described in detail in the Evidence Review. Briefly, there were three stages to this process:

- *Clinical question development.* Members of the GDG were asked to submit clinical questions to the NCC-C on issues covered by the project scope.
- *Literature searching.* All clinical questions were prioritised and were subject to either a systematic or a 'high-level' search.
- *Critical appraisal.* Finally all full papers relevant to each clinical question were appraised using the methodology described in the *NICE Guideline Development Methods* manual.

It should be noted that most of the published research on cancer topics focuses on clinical evaluations of treatment; little direct research has been carried out on the organisation and delivery of services.

In order to elicit the views of patients with skin tumours on current cancer service provision, a piece of research was commissioned by the GDG and NCC-C. Researchers at the Department of Social Medicine, University of Bristol, performed this study, the full results of which are given in the Evidence Review.

All the evidence reviews used to inform the manual are summarised in the document *Improving Outcomes for People with Skin Tumours including Melanoma: the Research Evidence*, which includes details of all the studies appraised. This document is available on a CD-ROM, a copy of which is included on the inside cover of the manual.

Additional complementary research, designed to quantify the potential cost of major changes in services, was carried out by the Centre for Economics and Policy in Health, Institute of Medical and Social Care Research (IMSCAR), at the University of Bangor. This work involves literature-searching, interviews with clinicians and managers, and analyses of costs.

The writing of the guidance manual was coordinated by the Chair and Clinical Lead of the GDG in accordance with all members of the GDG, assisted by Dr Fergus Macbeth, Dr Andrew Champion and Dr Mary Webb at the NCC-C.

The production of this guidance was funded by the National Institute for Health and Clinical Excellence (NICE), and has been subject to the full NICE consultation process.

People and organisations involved in production of the guidance

- 5.1 Members of the Guidance Development Group**
- 5.2 Organisations invited to comment on guidance development**
- 5.3 Researchers carrying out literature reviews and complementary work**
- 5.4 Expert advisers to the Guidance Development Group**
- 5.5 Reports commissioned to assist with guidance development**
- 5.6 Members of the Guideline Review Panel**

A5

Appendix 5.1

Members of the Guidance Development Group (GDG)

GDG Chair

Dr Julia Verne, Consultant in Public Health Medicine, South West Region

GDG Lead Clinician

Dr Dafydd Roberts, Consultant Dermatologist, Swansea NHS Trust

Group members

Dr Ernest Allan	Consultant Clinical Oncologist, The Christie Hospital, Manchester
Mr Andrew Caswell	Patient/Carer Representative, Macmillan Cancer Voices
Ms Gillian Godsell	Skin Cancer Clinical Nurse Specialist, University Hospitals NHS Trust, Nottingham
Dr Arthur Jackson	Associate Specialist in Dermatology, East & Mid Cheshire NHS Trusts; previously a general practitioner and nominated by the RCGP
Mrs Sheila Keatley	Patient/Carer Representative, Liverpool Cancer Support Centre
Mrs Jillian Moses	Practice Development Radiographer, Aberdeen Royal Infirmary
Mr Oliver Newbold	Commissioning Manager, Newark and Sherwood PCT

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Professor Julia Newton-Bishop	Consultant Dermatologist, St James' University Hospital, Leeds	<i>Improving Outcomes for People with Skin Tumours including Melanoma</i>
Mr Barry Powell	Consultant Plastic and Reconstructive Surgeon, St George's Hospital, London	<i>Appendix 5</i>
Dr David Slater	Consultant Dermatopathologist, Royal Hallamshire Hospital, Sheffield	
Mr James Smallwood	Central South Coast Cancer Network Lead Clinician, Southampton General Hospital	
Mrs Marion Stevenson-Rouse	Patient Carer Representative, MARC's Line, Wessex Cancer Trust	
Dr Paddy Stone	Consultant in Palliative Medicine, St George's Hospital, London	
Mr Martin Telfer	Consultant Maxillofacial Surgeon, York Hospitals NHS Trust	
Mrs Kathy Thompson	Senior Occupational Therapist, Cookridge Hospital, Leeds	



Appendix 5.2

Organisations invited to comment on guidance development

- 3M Health Care Limited
- Addenbrooke's NHS Trust
- Anglesey Local Health Board
- Association for Palliative Medicine of Great Britain and Ireland
- Association of Hospice and Specialist Palliative Care Social Workers
- Association of Surgeons of Great Britain and Ireland
- Association of the British Pharmaceuticals Industry (ABPI)
- Astron Clinica Limited
- Aventis Pharma
- Bard Limited
- Bath and North East Somerset PCT
- Bayer Healthcare
- Bedfordshire & Hertfordshire NHS Strategic Health Authority
- Birmingham Heartlands & Solihull NHS Trust
- Blaenau Gwent Local Health Board
- Boehringer Ingelheim Ltd
- Brighton & Sussex University Hospitals Trust

- Bristol South and West PCT
- British Association for Counselling and Psychotherapy
- British Association of Dermatologists, The
- British Association of Head and Neck Oncologists
- British Association of Oral and Maxillofacial Surgeons
- British Association of Otolaryngologists, Head & Neck Surgeons
- British Association of Plastic Surgeons
- British Dermatological Nursing Group
- British Dietetic Association
- British Lymphology Society
- British National Formulary (BNF)
- British Nuclear Medicine Society
- British Oculoplastic Surgery Society
- British Oncology Pharmacy Association
- British Psychological Society, The
- British Psychosocial Oncology Society
- British Society for Dermatological Surgery
- British Society for Dermatopathology
- British Society of Paediatric Radiology
- Buckinghamshire Hospital NHS Trust
- BUPA
- Cancer Research UK
- Cancer Services Collaborative 'Improvement Partnership' (CSCIP)
- Cancer Services Co-ordinating Group
- Cancer Voices



- CancerBACUP
- Changing Faces
- Chartered Society of Physiotherapy
- Clatterbridge Centre for Oncology NHS Trust
- Cochrane Skin Group
- College of Occupational Therapists
- Coloplast Limited
- ConvaTec
- Co-operative Pharmacy Association
- Countess of Chester Hospitals NHS Trust
- Department of Health
- DiaSorin Limited
- Dudley Group of Hospitals NHS Trust, The
- East Cambridgeshire and Fenland Primary Care Trust
- Eisai Limited
- Elan Pharmaceuticals Ltd
- Faculty of Public Health
- Frimley Park Hospital NHS Trust
- Galderma (UK) Ltd
- Gloucestershire Hospitals NHS Trust
- Gorlin Syndrome Group
- Guerbet Laboratories Ltd
- Guy's & St Thomas' NHS Trust
- Health Development Agency

- Healthcare Commission
- Help Adolescents with Cancer
- Help the Hospices
- Institute of Sport and Recreation Management
- Johnson & Johnson Medical
- Joint Committee on Palliative Medicine
- Leeds North East PCT
- Leeds Teaching Hospitals NHS Trust
- Macmillan Cancer Relief
- Mansfield District PCT
- Marie Curie Cancer Care
- Medeus Pharma Limited
- Medicines and Healthcare Products Regulatory Agency (MHRA)
- Mid Staffordshire General Hospitals NHS Trust
- Middlesbrough Primary Care Trust
- Mole Clinic Ltd, The
- National Alliance of Childhood Cancer Parent Organisations
- National Association of Assistants in Surgical Practice, The
- National Cancer Alliance
- National Cancer Network Clinical Directors Group
- National Cancer Research Institute (NCRI) Clinical Studies Group
- National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)
- National Kidney Federation (NFK)
- National Patient Safety Agency

- National Public Health Service – Wales
- Neurofibromatosis Association, The
- NHS Direct
- NHS Information Authority (PHSMI Programme)
- NHS Modernisation Agency, The
- NHS Quality Improvement Scotland
- North East Lincolnshire PCT
- Novartis Pharmaceuticals UK Ltd
- Pfizer Limited
- Princess Alexandra Hospital NHS Trust
- Queen’s Medical Centre, Nottingham University Hospitals NHS Trust
- Queen Victoria NHS Trust
- Roche Products Limited
- Rotherham Primary Care Trust
- Royal College of Anaesthetists
- Royal College of General Practitioners
- Royal College of General Practitioners Wales
- Royal College of Nursing (RCN)
- Royal College of Ophthalmologists
- Royal College of Paediatrics and Child Health
- Royal College of Pathologists
- Royal College of Physicians of London
- Royal College of Psychiatrists
- Royal College of Radiologists

- Royal College of Surgeons of England
- Royal College Patient Liaison Groups
- Royal Pharmaceutical Society of Great Britain
- Royal Society of Medicine, The
- Royal West Sussex Trust, The
- Royal Wolverhampton Hospitals NHS Trust, The
- Schering-Plough
- Scottish Intercollegiate Guidelines Network (SIGN)
- Sheffield Teaching Hospitals NHS Trust
- Shire Pharmaceuticals Limited
- Skin Care Campaign
- Skinship (UK)
- Society and College of Radiographers
- South Birmingham Primary Care Trust
- South Devon Health Care Trust
- Specialist Child and Adolescent Mental Health Service
- Tameside and Glossop Acute Services NHS Trust
- Teenage Cancer Trust, The
- Thames Valley Strategic Health Authority
- Tissue Viability Nurses Association
- UK Association of Cancer Registries
- UK Skin Lymphoma Group
- University Hospital Birmingham NHS Trust
- Velindre NHS Trust
- Walsall Primary Care Trust

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Appendix 5

- Welsh Assembly Government (formerly National Assembly for Wales)
- Welsh Cancer Services Coordinating Group
- Wessex Cancer Trust
- West of Cornwall Primary Care Trust

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A5

Report* commissioned to assist with guidance development

The skin cancer patient experience: a report for the NICE skin tumours service guidance – commissioned by the skin tumours GDG and the National Collaborating Centre for Cancer

A5

** This report is available in the Evidence Review that accompanies this Service Guidance*

Appendix 5.6

Members of the Guideline Review Panel

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A5

Glossary of terms

Actinic keratosis

A precancerous condition of thick, scaly patches of skin. Also called solar or senile keratosis.

Adjuvant therapy

Additional treatment that is added to increase the effectiveness of the main treatment.

Aetiology

The cause or origin of disease.

Allied health professional (AHP)

One of the following groups of healthcare workers: physiotherapists, occupational therapists, art therapists, chiropodists/podiatrists, dietitians, drama therapists, music therapists, orthoptists, paramedics, prosthetists/orthotists, radiographers, speech and language therapists.

Allogeneic/allogenic transplantation

A procedure in which a person receives cells from a genetically similar, but not identical, donor. This is often a sister or brother, but could be an unrelated donor.

Atypical naevi

A condition where a person has a number of moles that are generally larger than ordinary moles and have irregular and indistinct borders. Their colour frequently is not uniform and ranges from pink to dark brown; they are usually flat, but parts may be raised above the skin surface. If the condition runs in the family, it may be called familial dysplastic naevus syndrome.

Autologous transplantation

A procedure in which a person's cells are removed, stored, and later given back to the same person.

Autosomal

Refers to a chromosome that is not involved in determining sex. If a disorder is autosomal it affects both males and females equally.

Basal cell carcinoma

A type of skin cancer that arises from the basal cells, small round cells found in the lower part (or base) of the epidermis, the outer layer of the skin.

Benign

Not cancerous; not malignant.

Biopsy

Removal of a sample of tissue or cells from the body to assist in the diagnosis of a disease.

Bowen's disease

A skin disease marked by scaly or thickened patches on the skin. The patches often occur on sun-exposed areas of the skin and in older white men. These patches may become malignant. Also sometimes called precancerous dermatosis, precancerous dermatitis or carcinoma in situ.

Brachytherapy

Radiotherapy delivered by a temporary or permanent implant of radioactive material into a tissue or organ.

Breslow thickness

A measuring scale of thickness for malignant melanomas, measured from the top layer of skin to the bottom of the tumour. The deeper the melanoma has grown, the more likely it is that some cells may have spread through the blood stream or lymphatic system.

Cancer

Growth of altered body cells that keep on growing, which is able to spread from where it started to another part of the body.

Cancer Networks

The organisational model for cancer services to implement the NHS Cancer Plan, bringing together health service commissioners and providers, the voluntary sector and local authorities. There are currently 34 Cancer Networks in England covering between 600,000 and 3 million population (two-thirds serve a population of between 1 and 2 million people).

Carcinoma

Cancer of the skin tissue that covers all the body organs. Most cancers are carcinomas.

Cautery

The application of a hot instrument, an electrical current, a caustic substance or other substance to kill certain types of small tumours or to seal off blood vessels to stop bleeding.

Chemoprophylaxis

The use of a drug or chemical to prevent future occurrences of a disease.

Chemotherapy

The use of drugs that kill cancer cells, or prevent or slow their growth.

Clinical oncologist

A doctor who specialises in the treatment of cancer patients, particularly through the use of radiotherapy, but may also use chemotherapy.

Clinical oncology

The specialist treatment of cancer patients, particularly through the use of radiotherapy, but may also be through the use of chemotherapy.

Cohort studies

Research studies in which groups of patients with a particular condition or specific characteristic are compared with matched groups who do not have it.

Computed tomography (CT)

An X-ray imaging technique.

Cryosurgery

A procedure performed with an instrument that freezes and destroys abnormal tissue.

Cryotherapy

A treatment that uses a cold temperature to remove cells or tissue by freezing.

Curettage

Removal of tissue with a curette, a spoon-shaped instrument with a sharp edge.

Cutaneous T-cell lymphoma

A disease in which certain cells of the lymph system (called T lymphocytes) become cancerous and affect the skin.

Cytopathologist

A doctor who specialises in the study of disease changes within individual cells or cell types.

Cytotoxic

Cell-killing.



Dermatofibrosarcoma protuberans

A type of tumour that begins as a hard nodule and grows slowly. These tumours are usually found in the dermis (the inner layer of the two main layers of tissue that make up the skin) of the limbs or trunk of the body. They can grow into surrounding tissue but do not spread to other parts of the body.

Dermatologist

A doctor who specialises in the diagnosis and treatment of skin disorders.

Dermatology

The specialist treatment of skin disorders.

Dermatopathologist

A pathologist with special training and expertise in the diagnosing of skin diseases.

Dermatopathology

The study of the pathology of the skin.

Dermatoscope

A tool like a hand-held microscope used by doctors to view a mole or suspicious spot on living skin.

Dermatoscopy

Skin scoping or observing the skin directly using a special microscope, usually performed on a mole or suspicious spot on living skin.

Dermis

The lower or inner layer of the two main layers of tissue that make up the skin.

Diagnostic radiographer

The role of the diagnostic radiographer is to work closely with other specialists, to provide safe and accurate imaging examinations, to give patients information and support and to discuss possible side effects and care.

Dietitian

The healthcare professional responsible for the planning and managing of the patient's diet in hospital and providing dietary advice for a wide range of medical conditions.

Ear, nose and throat (ENT)

Diagnosis and treatment of diseases of the ear, nose and throat.

Electrodesiccation

A surgical method of drying out tissue by touching it with a needle-like electrode that passes electric current into the tissue.

Epidemiology

The study of populations in order to determine the frequency and distribution of disease and to measure risks.

Excision

Removal by surgery.

Gorlin's syndrome

An inherited condition that can increase an individual's chance of developing basal cell carcinoma. Also called basal cell nevus syndrome.

High-risk basal cell carcinoma

Those that have a high recurrence rate after treatment. There are several factors that may have an effect on recurrence rate including histological sub-type, other histological features, site, and other patient and tumour features.

Histological sub-type

- Morphoeic – linear groups of cancer cells with surrounding scarring; clinically this causes a thickened and hardened skin
- Infiltrating – like morphoeic but with less scarring
- Micronodular – very small groups of cancer cell
- Basosquamous carcinoma – a skin cancer with both basal and squamous elements

Histological features

- Perineural invasion
- Invasion below dermis

Sites

- Nose and paranasal folds
- Periocular
- Ears
- Scalp and temples
- Lips

Other factors

- Size > 2 cm
- Immunosuppression
- Genetic disorders such as Gorlin's syndrome
- Previously treated lesion

High-risk squamous cell carcinoma

Those that are high risk have a high recurrence rate after treatment and may metastasise.

Histological features

Poorly differentiated, perineural invasion, depth greater than 4 mm or extending to subcutaneous tissue (Clark level 5)

Sites

Lip, ears, non-sun-exposed sites, e.g. penis, scrotum and soles of feet; in areas of previous injury, e.g. burns, irradiation and chronic ulcers

Other factors

Greater than 2 cm diameter, immunosuppression, previously treated lesion

Histology

The study of body tissue and cells by examination under a microscope to find out what type of body tissue it is, or if a cancer, what type of body cells the cancer cells most look like.

Histopathologist

A doctor who specialises in examining tissue samples microscopically in order to make a diagnosis and ensure tumour excision is complete.

Histopathology

The study of microscopic changes in diseased tissues.

Hyfrecation

A surgical method that involves using an electrical current to burn a skin lesion or tumour.

Immunocompromised

Having a weakened immune system as a result of certain diseases or treatments.

Immunophenotyping

A process used to identify cells, based on the types of antigens or markers on the surface of the cell. This process is used to diagnose specific types of leukaemia and lymphoma by comparing the cancer cells to normal cells of the immune system.

Immunosuppression

Suppression of the body's immune system and its ability to fight infections or disease. Immunosuppression may be deliberately induced with drugs. It may also result from certain diseases such as lymphoma or from anticancer drugs.

Immunotherapy

Treatment by stimulating or restoring the body's own immune system.

In situ

Localised and confined to one area; often used to describe a cancer that has not spread deeply.

Isolated limb infusion

A technique that may be used to deliver anticancer drugs directly to an arm or leg. The flow of blood to and from the limb is stopped temporarily and anticancer drugs are injected directly into the blood of the limb. This allows the person to receive a high dose of drugs in the area where the cancer occurred.

Isolated limb perfusion

A technique in which blood vessel surgery is used to temporarily isolate the circulation of an arm or leg from the rest of the body. The blood is mixed with high doses of chemotherapy drugs, recirculated through a heart–lung machine, and heated for a period of time to enhance the drug's potency. The treated blood is recirculated to the affected limb.

Kaposi's sarcoma

A type of cancer characterised by the abnormal growth of blood vessels that develop into skin lesions or occur internally.

Lentigo maligna

Flat, mottled, tan-to-brown freckle-like spots with irregular borders, usually appearing on the face or other sun-exposed areas of older persons, which typically enlarge slowly for many years before cancer appears. Also known as Hutchinson's or melanotic freckle.

Lesion

An area of abnormal tissue.

Lymphadenopathy

Disease or swelling of the lymph nodes.

Lymphoedema

A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed or treated with radiation.

Lymphoma

Cancer that begins in cells of the immune system, the lymphocytes (a type of white blood cell).

Lymphomatoid papulosis

A rare skin disorder that is characterised by crops of benign, self-healing skin lesions.

Magnetic resonance imaging (MRI)

A non-invasive method of imaging, which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).

Malignant

Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body.

Margin

The edge or border of the tissue removed in cancer surgery.

Maxillofacial

The speciality that combines full surgical training with dental expertise for the treatment of diseases, injuries, tumours and deformities of the face and jaws.

Medical oncology

The specialist treatment of cancer patients through the use of chemotherapy and, for some tumours, immunotherapy.

Melanoma

A form of skin cancer that arises in melanocytes, the cells that produce pigment.

Merkel cell carcinoma

A rare type of cancer that forms on or just beneath the skin.

Meta-analysis

The statistical analysis of the results of a collection of individual research studies in order to add the findings together.

Metachronous

At different times.

Minimum dataset

A widely agreed-upon and generally accepted set of terms and definitions making up a core of data acquired for medical records and used for developing statistics for different types of analyses and users.

Mohs surgery

A surgical technique used to treat skin cancer. Individual layers of cancerous tissue are removed and examined under a microscope one at a time until all cancerous tissue has been removed.

Morbidity

A diseased condition or state.

Mortality

Either a) the condition of being subject to death or b) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000.

Mycosis fungoides

A type of non-Hodgkin's lymphoma that first appears on the skin and can spread to the lymph nodes or other organs such as the spleen, liver or lungs.

Neoplasm

An abnormal mass of tissue that results from excessive cell division.

Non-melanoma skin cancer

Skin cancer that arises in basal cells or squamous cells but not in melanocytes (pigment-producing cells of the skin).

Occupational therapist

A health professional trained to help people who are ill or disabled learn to manage their daily activities.

Oculoplastic surgeon

A doctor who specialises in the restoration, reconstruction, correction or improvement of the shape and appearance of the eye.

Oncologist

A doctor who specialises in treating cancer.

Oncology

The study of the biological, physical and chemical features of cancers. Also the study of the causes and treatment of cancers.

Orthosis

A device that is used to protect, support, or improve function of parts of the body that move.

Orthotic

See Orthosis.

Palliative

Anything that serves to alleviate symptoms caused by the underlying cancer but that is not expected to cure it.

Palliative care

Active, holistic care of patients with advanced, progressive illness that may no longer be curable. The aim is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable in earlier stages of the cancer journey in association with other treatments.

Paranasal

Around or near the nasal passages.

Pathologist

A doctor who examines cells and identifies them. The pathologist can tell where in the body a cell comes from and whether it is normal or a cancer cell. If it is a cancer cell, the pathologist can often tell what type of body cell the cancer developed from. In a hospital practically all the diagnostic tests performed with material removed from the body are evaluated or performed by a pathologist.

Perineural

Around a nerve or group of nerves.

Periocular

Around the eyes.

Photodynamic therapy

Treatment with drugs that become active when exposed to light. These drugs kill cancer cells.

Photopheresis

A procedure in which blood is removed from the body and treated with ultraviolet light and drugs that become active when exposed to light. The blood is then returned to the body.

Physiotherapist

A specialist trained in using exercise and physical activities to condition muscles and improve level of activity.

Plastic surgeon

A doctor who specialises in surgery to correct damage to the skin. For example, reducing the amount of scarring or disfigurement that may happen because of surgery to treat a skin tumour.

Positron emission tomography (PET)

A highly specialised imaging technique using a radioactive tracer to produce a computerised image of body tissues to find any abnormalities. PET scans are sometimes used to help diagnose cancer.

Precancerous

A term used to describe a condition that may (or is likely to) become cancer. Also called premalignant.

Prognosis

A prediction of the likely outcome or course of a disease; the chance of recovery or recurrence.

Prognostic factor

Patient or disease characteristics, e.g. age or co-morbidity, that influence the course of the disease under study.

Prosthesis

An artificial device used to replace a missing part of the body.

Prosthetic

See Prosthesis.

Protocol

An agreed policy that defines appropriate action.

Psychological

Adjective of psychology, which is the scientific study of behaviour and its related mental processes. Psychology is concerned with such matters as memory, rational and irrational thought, intelligence, learning, personality, perceptions and emotions and their relationship to behaviour.

Psychologist

A specialist who can talk with patients and their families about emotional and personal matters, and can help them make decisions.

Psychosocial

Concerned with psychological influences on social behaviour.

Radiologist

A doctor who specialises in creating and interpreting pictures of areas inside the body. An interventional radiologist specialises in the use of imaging techniques to assist treatment, e.g. the insertion of intravenous catheters.

Radiology

The use of radiation (such as X-rays) or other imaging technologies (such as ultrasound and magnetic resonance imaging) to diagnose or treat disease.

Radiotherapy

The use of radiation, usually X-rays or gamma rays, to kill cancer cells and treat tumours.

Randomised controlled trial (RCT)

A type of experiment that is used to compare the effectiveness of different treatments. The crucial feature of this form of trial is that patients are assigned at random to groups that receive either the interventions being assessed or control treatments. RCTs offer the most reliable (i.e. least biased) form of evidence of effectiveness.

Retinoid

Vitamin A or a vitamin A-like compound.

Sarcoma

A cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

Scintigraphy

A diagnostic method. A radioactive tracer is injected into the body. The radiation it sends out produces flashes of light on a scintillator (instrument used to detect radioactivity), and they are recorded. Also called radionuclide scanning.

Sentinel (lymph) node biopsy

Removal and examination of the sentinel node(s) (the first lymph node(s) to which cancer cells are likely to spread from a primary tumour). To identify the sentinel lymph node(s), the surgeon injects a radioactive substance or blue dye, or both, near the tumour. The surgeon then uses a scanner to find the sentinel lymph node(s) containing the radioactive substance or looks for the lymph node(s) stained with dye. The surgeon then removes the sentinel node(s) to check for the presence of cancer cells.

Sézary syndrome

A form of cutaneous T-cell lymphoma.

Squamous cell carcinoma

Cancer that begins in squamous cells. Squamous cells are found in the tissue that forms the surface of the skin, the lining of the hollow organs of the body, and the passages of the respiratory and digestive tracts. Also called epidermoid carcinoma.

Supportive care

Care that helps the patient and his or her family and carers to cope with cancer and its treatment, and in the case of the family and carers, with bereavement. It aims to help the patient maximise the benefits of treatment and to provide the best possible quality of life.

Surgical oncologist

A doctor who specialises in using surgery to treat cancer.

Synchronous

At the same time.

Systemic therapy

Treatment that reaches and affects cells throughout the body rather than targeting one specific area; for example, chemotherapy.

Therapeutic radiographer

The role of the therapeutic radiographer is to work closely with other specialists, to deliver the radiotherapy as prescribed, to give patients information and support and to discuss possible side effects and care.

Topical therapy

Treatment with drugs in a lotion, ointment or cream applied to the skin.

Tumour

A mass of excess tissue that results from abnormal cell division. Tumours perform no useful body function.

Xeroderma pigmentosum

A genetic condition characterised by sensitivity to all sources of ultraviolet radiation.

Abbreviations

AHP	allied health professional
AIDS	acquired immune deficiency syndrome
AJCC	American Joint Committee on Cancer
AK	actinic keratosis
AMS	atypical mole syndrome
BAD	British Association of Dermatologists
BCC	basal cell carcinoma
CME	continuing medical education
CMO	Chief Medical Officer
CNS	clinical nurse specialist
CPD	continuing professional development
CT	computed tomography
CTCL	cutaneous T-cell lymphoma
DH	Department of Health
ENT	ear, nose and throat
EORTC	European Organisation for Research and Treatment of Cancer
EQA	external quality assessment
GDG	Guidance Development Group
GP	general practitioner
GPwSI	general practitioner with a special interest
HAART	highly active antiretroviral therapy
HDA	Health Development Agency
HES	Hospital Episodes Statistics
HIV	human immunodeficiency virus
ICD	International Classification of Diseases
ILI	isolated limb infusion
ILP	isolated limb perfusion
IT	information technology
ITU	intensive care unit

KS	Kaposi's sarcoma
LHB	local health board
LSMDT	local hospital skin cancer multidisciplinary team
MCC	Merkel cell carcinoma
MDT	multidisciplinary team
MM	malignant melanoma
MRI	magnetic resonance imaging
NCC-C	National Collaborating Centre for Cancer
NCRI	National Cancer Research Institute
NCRN	National Cancer Research Network
NICE	National Institute for Health and Clinical Excellence
NMSC	non-melanoma skin cancer
NSF	National Service Framework
ONS	Office for National Statistics
PCT	primary care trust
PDT	photodynamic therapy
PEDW	Patient Episode Database in Wales
PET	positron emission tomography
RCGP	Royal College of General Practitioners
SCC	squamous cell carcinoma
SHA	strategic health authority
SIGN	Scottish Intercollegiate Guidelines Network
SNB	sentinel node biopsy
SSMDT	specialist skin cancer multidisciplinary team
UKACR	United Kingdom Association of Cancer Registries
UV	ultraviolet
WHO	World Health Organization
XP	xeroderma pigmentosum

Improving Outcomes for People with Skin Tumours including Melanoma

Cancer service guidance supports the implementation of *The NHS Cancer Plan* for England,¹ and the NHS Plan for Wales *Improving Health in Wales*.² The service guidance programme was initiated in 1995 to follow on from the Calman–Hine Report, *A Policy Framework for Commissioning Cancer Services*.³ The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.

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