

**SKIN CANCER –
IMPROVING PREVENTION,
TREATMENT AND CARE**

A REPORT OF THE
ALL PARTY PARLIAMENTARY GROUP ON SKIN

London
November 2008

SKIN CANCER – IMPROVING PREVENTION, TREATMENT AND CARE

This report was prepared by a panel of independent experts in skin disease on behalf of the officers of the All Party Parliamentary Group on Skin (APPGS). Both the officers and expert group are listed at the back of the report. APPGS is supported by grants from the Skin Care Campaign, British Association of Dermatologists and Primary Care Dermatology Society and by individual subscriptions from external members of the Group. None of these latter subscriptions, several of which were from pharmaceutical companies, exceeded £1,000. These funding sources support the APPGS' Secretariat, which provided administrative assistance in the preparation and publication of this report.

**A REPORT OF THE
ALL PARTY PARLIAMENTARY GROUP ON SKIN**

London
November 2008

SKIN CANCER IMPROVING PREVENTION, TREATMENT AND CARE

CONTENTS

Chapter		Page
	Foreword	
1.0	Executive Summary	1
2.0	Summary of Policy Recommendations	1
3.0	Background to Skin Cancer	2
4.0	The Patient's Perspective	4
5.0	Awareness Campaigns and Prevention	5
6.0	Sunbeds	9
7.0	Early Diagnosis and Imaging Techniques	11
8.0	Generalist Care	14
9.0	Specialist Care	16
10.0	Pharmacy in Primary Care	19
11.0	Models of Care	20
12.0	Skin Cancer Clinical Nurse Specialists	22
13.0	Appendices	25
	Appendix I. Specialist Advisory Panel	
	Appendix II. References	
	Appendix III. List of Oral Evidence	
	Appendix IV. List of Written Evidence	
	Appendix V. Index of previous APPGS Reports	
	Appendix VI. Officers of the APPGS	

Foreword

The All Party Parliamentary Group on Skin was established in 1994 and has a large and active membership, including Members of Parliament from all political parties, Members of the House of Lords, health professionals, patient groups and pharmaceutical companies. The Group was set up to raise awareness and understanding of skin issues in Parliament and to seek improvement of delivery of treatment to those with skin diseases.

I have been aware for some time about concerns surrounding skin cancer, its causes and treatment and these have been raised regularly in Parliament in the past couple of years, notably in respect of sunbed use and wider prevention issues.

Skin cancer raises complex issues that evoke emotion amongst those with an interest, not least because of the feeling that many skin cancers are preventable in the first place and successfully treatable if the appropriate structures are in place.

This report focuses on various key issues raised by the Group. We have tried to look at the underlying elements to draw our conclusions, which have been verified by a strong panel of stakeholders in the skin care field. The report has been widely consulted on across patient groups, clinicians, and other stakeholders. We have gone to very great lengths to build a strong evidence base, ensuring that any conclusions presented in the report are accurate and balanced.

We hope that the report will both stimulate debate and prompt moves to raise awareness and improve NHS services for the disease.

The APPGS welcomes any further feedback or comments from stakeholders.

A handwritten signature in black ink that reads "Bruce George". The signature is written in a cursive style with a horizontal line underneath the name.

Rt Hon Bruce George MP
Chair, All Party Parliamentary Group on Skin
November 2008

SKIN CANCER

IMPROVING PREVENTION, TREATMENT AND CARE

1.0 Executive Summary

The All Party Parliamentary Group on Skin (APPGS) reviewed all of the main issues relating to skin cancer in an enquiry lasting nearly a year. Clear features of concern emerged, the most important of which are:

- the need for a better funded public prevention campaign
- more consultant and nursing expertise to treat people with skin cancers
- tougher rules around sunbed use
- better co-ordination in NHS commissioning for cancer services.

It was particularly noted that much skin cancer is avoidable in the first place and that treatment can be highly effective if the cancer is caught early enough and appropriately treated.

Given the number of cancer cases, the expert advisers to the APPGS were concerned that the condition appears to have been accorded a much lower priority – over many years - than it surely deserves, both in efforts to prevent it and in the planning of services to treat it.

The Group has therefore made a series of recommendations which would go a long way to rectifying this situation. If the NHS is to achieve world class commissioning in the area of skin cancer, then it is vital that these recommendations are taken forward in the months and years to come.

2.0 Summary of Policy Recommendations

Members of the All Party Group's oversight group and the special advisers to this enquiry voted for their top ten recommendations. The list set out below represents their choices and there was high degree of unanimity in these. They are listed in the order that they appear in the report.

Recommendation: More consultant dermatologists are required to bring numbers up towards European levels

Recommendation: Greater emphasis should be placed on improving education amongst all those who have contact with skin conditions and especially in primary care

Recommendation: VAT should be reduced on sunscreens

Recommendation: A comprehensive review of skin cancer prevention should be undertaken by NICE, leading to the creation of one recognised sun care awareness brand, independent of any one charity or organisation, available to all without copyright issues and properly resourced by Government

Recommendation: A central resource of suitable leaflets and posters should be available, free of charge, for health education purposes

Recommendation: The HSE's proposed new advice should be mandatory, including a ban on use of sunbeds by those under 18 and on unsupervised coin operated beds

Recommendation: Public bodies, such as local authority sports centres, should not offer sun beds as this influences public perception that such a facility is healthy

Recommendation: An acceptable level of training for clinic staff in private mole clinics must be agreed between Skin Cancer multi-disciplinary teams (MDTs) and those providing the services, to ensure quality of service provision

Recommendation: All regions should have a dermatological surgeon trained in Mohs' surgery

Recommendation: Each Dermatology unit should have a CNS in Skin Cancer at a ratio of 1 full-time employee per 160,000 population.

3.0 Background to Skin Cancer

3.1 The incidence of skin cancer, both melanoma and non melanoma skin cancer (NMSC), is rising throughout the world, with NMSC being the most common of all cancers. Combined, these two account for almost one third of cancer. For melanoma alone, the annual increase is estimated to be between 3 and 7%, with mortality rates increasing less quickly¹. These estimates suggest a doubling of rates every ten to twenty years

3.2 The incidence of mole skin cancer (malignant melanoma (MM)) in England increased by 31.5% in men and 22% in women between 2001 and 2005 and this trend is continuing².

3.3 A three-fold increase in basal cell carcinoma (BCC), the commonest type of non-mole skin cancer, is predicted over the next ten to twenty years and this does not take into account the effects of climate change³.

3.4 Recent evidence shows that no sun tan is safe and everyone needs to appreciate that a sun tan is a sign of skin damage caused by UV light, whether from the sun or a sunbed⁴.

3.5 Melanoma is the fastest rising cancer in the UK and, according to CRUK^{1,5}, causes more than 2,300 deaths per annum and is more prevalent than, for example, cervical cancer, which has been much in the news in recent months⁶

3.6 Early detection of melanoma vastly improves survival rates.

3.7 Exposure to ultraviolet radiation (UVR), the principal source of which is the sun, is known to be the major risk factor for skin cancer. The link between cumulative, life long, sun exposure and the development of non-melanoma skin cancer is well established. MM seems to be most strongly linked to intermittent exposure to high-intensity sunlight, often resulting in sunburn. The reasons for this link are not well understood.

3.8 Sunbeds and sunlamps are also a source of UVR.

3.9 A recent study at Ninewells Hospital and Medical School, Dundee, showed that regular users of sunbeds face an increased risk of developing skin cancer⁷.

3.10 Research has indicated that there is a link between sunburn in childhood and the development of MM in later life. The implication of this link for patients, their family members and society is clear.

3.11 To compound this, it is common in the UK, for school sports days to be conducted in the midday sun and for school playgrounds and playing fields to lack shady areas. Furthermore, the fashion for short or shaved hair in young men greatly increases the risk of sun damage to the head⁸.

3.12 A consensus of opinion is that, in many junior schools, teachers are reluctant to, or in some cases will refuse to, apply sunscreens to their pupils, for fear of being accused of abuse⁷.

3.13 Research conducted by the Teenage Cancer Trust⁹ showed that teenagers' levels of awareness about how to protect themselves in the sun was low and they desperately need educating about this. This study found that:

- 41% of teenagers never used sun cream when in the UK
- 75% of UK teenagers admitted to burning in hot weather and nearly 80% admitted to not wearing sun cream every time they were exposed to the sun
- 48% were unaware of which factor sun cream they should be using
- Almost 50% of teenagers admitted to not being concerned about skin cancer
- Playing sport outdoors was a time when both boys and girls were particularly careless - 84% of those surveyed were reluctant to apply sun cream, with 32% of them stating that it was not a top priority.

3.14 The vast majority of skin cancers are avoidable. There is a huge disparity in current spending on prevention and on treatment of skin cancer and it is not acceptable that, according to Parliamentary answers, the DoH spends £75million on treatment for skin cancer and just £0.11million on prevention. In 2007/2008 Government funding for the SunSmart campaign dropped by 21% from the previous year.

3.15 Sunscreens are expensive and there may be a significant disincentive to use these, especially in more deprived areas and/or where there are a number of children in the family. It is important that the cost of these is reduced as far as possible and one immediate way to achieve this would be to cut the VAT rate charged on sunscreens¹⁰.

3.16 The diagnosis and management of most skin cancers will continue to be performed by specialists, usually in hospital settings. However the GP is the 'gatekeeper' to such services and is responsible for the crucial initial assessment and decision about referral for specialist care¹¹.

3.17 The National Institute for Clinical Excellence (NICE) cancer service guideline, Improving Outcomes in Skin Cancer¹² recommends that all suspected MMs, squamous cell carcinomas (SCCs) and high risk BCCs should be referred to specialist teams. It is recommended that these referrals are made either urgently - using the 2 week wait referral - or, for suspected BCC, as a routine referral. Low risk BCCs can be referred to accredited GPs with a special interest (GPwSI) cancer

clinicians, where these services are available. GPs should be able to diagnose and manage pre-malignant skin lesions (for example solar keratoses and Bowen's disease).

3.18 It is known that undergraduate medical education in skin disease is poor (see previous APPGS reports) and training in skin lesion recognition for GPs limited¹³.

3.19 The number of dermatologists in the UK - at 420 for a population of 60 million, a ratio of 1:135,000 - is smaller than in other European countries. In France this ratio is 1:17,714 and Spain 1:43,000, although it should be noted that direct comparisons can be misleading here because of the differences in provider systems¹¹.

3.20 For the UK, this is unlikely to be enough, given the rising epidemic of skin cancer, the fact that a large proportion of all GP consultations include a skin problem and given that the range of therapies now available for inflammatory skin diseases means that much more can be done for this group as well.

Recommendation: The standard of care delivered to patients with skin cancer should be the same whether that care is delivered in primary or secondary care, by private contractors working for the NHS or in private practice; care should be in line with existing NICE and other professional guidance

Recommendation: More consultant dermatologists are required to bring numbers up towards European levels

Recommendation: Greater emphasis should be placed on improving education amongst all those who have contact with skin conditions, especially in primary care

Recommendation: VAT should be reduced on sunscreens to the minimum 5% allowed under EU law to reduce disincentives to use, particularly in deprived areas.

4.0 The Patient's Perspective

Background

4.1 To be told that they have cancer is one of the worst diagnoses that anyone can hear. Only a careful explanation and clear treatment plan, whether active or palliative, may make it more bearable and understandable. For someone with newly diagnosed cancer there should ideally be someone available to be with the patient and, when appropriate, to explain what their actual diagnosis means and what actions will be taken. Experience and research in oncology suggests that a Clinical Nurse Specialist is best placed to be this person once the physician has made the diagnosis¹⁴.

Support and advice

4.2 As there are different types of skin cancer, the patient must receive information as to what their precise diagnosis is and efforts should be made to ensure that they have heard and understood properly. However, it may be very difficult for the patient to take in all they are told, so supplementary written information must be available for them to take away and the opportunity to contact the CNS made available.

Recommendation: All current patient information should be evaluated. Department of Health funding should be made available to collate information and produce the

best possible patient information leaflets for each diagnosis, perhaps using existing high quality leaflets as the basis of this

Recommendation: A central library should be established and one organisation delegated responsibility for maintaining and distributing information effectively.

5.0 Awareness Campaigns and Prevention

Background

5.1 In 1993, the Health Education Authority (HEA) commenced a national sun awareness Programme in the UK – the *Sun Know How* campaign, funded by the Department of Health (DH). The campaign supported a network of local health professionals, who distributed the messages regionally, as well as seeking to obtain media coverage.

5.2 Department of Health spending on sun safety messaging from 1999 to 2000 was £543,000. In 2000-1 this was reduced to £50,000. In 2001-2, funding was estimated at £126,000 including £35,000 used to provide the meteorological office with UV information for public weather forecasts. Before the withdrawal of funding, *Sun Know How* campaign personnel established robust working relationships with Multidisciplinary Skin Cancer Teams around the UK. Working together they developed excellent skin cancer health promotion/education material that was easily accessible, free and importantly, unbranded with any one organisation's name, so it could be utilised by all Health Promotion Units around the UK.

5.3 In December 2002, it was announced that £100,000 would be provided by the Department of Health (DoH), the National Assembly of Wales and the Health Promotion Board of Scotland to fund a UV health promotion programme, The *SunSmart* Campaign, to be run on their behalves by Cancer Research UK in 2003-4. This was to replace the *Sun Know How* campaign.

5.4 The majority of *SunSmart's* funding has recently been obtained from the DoH (under section 64), with smaller contributions from the Welsh, Scottish and Northern Ireland Governments.

5.5 Funding for the *SunSmart* campaign to date has been as follows:

£20,000 for 2003-4

£72,000 for 2004-5

£145,000 for 2005-6

£150,000 for 2006-7

£104,000 for 2007-8

5.6 Subject to approval by Parliament, Cancer Research UK will receive £110,000 for the *SunSmart* campaign in 2008-9 and £115,000 in 2009-10¹⁵.

Evidence

5.7 It is agreed that

- skin cancers are the most common group of cancers
- incidence is rising

- treatment is costly
- costs increase with late detection
- many such cancers are preventable.

5.8 The DoH must continue funding a national education campaign relating to both prevention and early detection. However, the structure and funding of the campaign could be improved to address certain issues.

5.9 As so many organisations promote sun safety messages (including individual healthcare professionals/teams, CRUK, Marc's line etc), it is impossible to gauge the impact of the DoH funded *SunSmart* campaign in isolation. Any statistics revealing improvements in people's attitudes to sun safety cannot be attributed solely to any one source as this would not take into account the extensive media coverage dedicated to other campaigns or individuals promoting the same themes.

Problems

5.10 Inadequate funding. The current SunSmart campaign does not receive the same level of funding, in real or actual terms, as *Sun Know How* did, and current funding is grossly inadequate¹⁶. Furthermore, no other skin cancer campaigns receive any government funding, despite being a vital source of information for the public, media and health professionals.

5.11 Melanoma, the deadliest form of skin cancer, represents alone some 3% of all cancers and this figure doesn't take into account the other 70,000 or more cases of skin cancer that are diagnosed annually^{1,3}. Melanoma is the most common cancer in young adults (aged 15-34), is largely preventable and may be curable if diagnosed and treated early.

5.12 In comparison 2,700 women were diagnosed with cervical cancer in the UK in 2004, which accounts for 2% of UK cancer¹. Expenditure on cervical cancer health promotion and screening is vast by comparison with that spent on health promotion for skin cancer and has produced a steady reduction in the death rate for cervical cancer. Cervical screening - including the cost of treating cervical abnormalities - has been estimated to cost around £157 million a year in England¹⁷.

5.13 Inadequate data collection. The Cancer Reform Strategy¹⁸ states, "The Department of Health stands ready to fund and support high quality health services research using data generated by the national cancer intelligence network". Data collection alone for skin cancer is deficient and more resources are needed to research the causation, prevention and treatment of skin cancer^{1,19}. As with other cancers, data collection needs to be developed and centralised – providing evidence of incidence, local anomalies, death rates and successful interventions¹². DH and voluntary sector research monies must be made more readily available for research into the causes, prevention and treatment of skin cancer. The British Skin Foundation, for example, might perhaps be encouraged to fund more skin cancer-specific research perhaps with matching central Government or MRC funding.

5.14 Inconsistent Messages. Many organisations, charities, companies and health professionals are working on campaigns, each using their own messages, slogans, literature and branding. This leads to confusion of messages. For example,

sunscreen manufacturers' campaigns may focus on the importance of sunscreen, rather than staying out of the sun or wearing protective clothing, and the reverse for UV-protective clothing manufacturers.

5.15 Fragmented Resources. *SunSmart* is just one of many skin cancer resources accessed by the public and healthcare professionals, each offering different benefits. For example, other organisations/campaigns are better equipped robustly to work with Health Promotion Units, or to access specialists for media interviews and up-to-date information to guide the campaign. These resources and different skills are currently not pooled under the umbrella of one campaign.

Solutions

5.16 The evidence presented confirmed that most organisations working in this field agree that the UK needs a government funded, standardised campaign, that can be used by all charities, health educationalists, consultants, nurses, pharmacists, companies, hospitals, local councils, occupational health professionals, cancer networks, schools and more, without any conflict of interests arising from branding.

5.17 The aim of a successful campaign would be to decrease the incidence of skin cancer by providing:

- specific prevention messages about skin care, sun damage, sun avoidance, use of shade and effective covering-up
- easy to use early notice guidance about changes in moles, lesions and the skin e.g: the British Association of Dermatologists (BAD's) "ABCD-Easy rules of mole checks"
- a clear message that "if in doubt, get it checked out" by your GP

5.18 The campaign should be guided by a group of experts working in the field of sun safety and skin cancer, to allow for the most knowledgeable advice. Such a steering group should have access to health education experts, public health experts, dermatologists, primary care clinicians including pharmacists, DH representatives, Skin Cancer Nurse Specialists, Surgeons, Photobiologists, charity representatives, and the relevant PR/marketing advisors, as well as other relevant parties currently working in the field of sun safety promotion.

5.19 Once the campaign focus and messaging had been established, the content could be used and distributed by all relevant organisations. One possible model is "Slip-Slop-Slap" - the highly successful Australian sun safety campaign launched in 1981 by the Cancer Council Australia that encouraging the public to "slip on a shirt, slip on sunscreen, and slap on a hat" when they went out into the sun.

5.20 It is thought to be Australia's best known health message and is widely credited with the decrease in skin cancer figures and greatly increased public knowledge on sun protection since its initiation 17 years ago.

5.21 Recent research suggests that melanoma rates and deaths from the disease have stabilized in Australia. In 1996, an Australian research group, writing in the British Medical Journal, published what it said was the first evidence that melanoma deaths in Australia plateaued in 1985 after rising steadily for more than 50 years²⁰.

The investigators predicted deaths from skin cancer will drop in coming years and linked the change to early detection and the “Slip-Slop-Slap” campaign. They added that the findings “provide encouragement to public health programmes designed to decrease exposure to the sun and promote earlier diagnosis”.

5.22 “Slip-Slop-Slap” has been extensively used by various cancer councils, charities and organisations and, thanks to its memorable format and lack of ‘ownership’, has been widely distributed by all parties involved in cancer prevention. The UK needs a Government-funded, non-branded campaign that can be used and distributed by all interested groups. This would allow consistency of messaging.

5.23 Such a multidisciplinary approach could involve local authorities and regional directors of public health, so as to include schools policies for education of pupils and teachers, as well as influencing the design of outdoors recreation areas in schools, parks and public spaces to ensure the provision of shade areas.

Skin cancer self awareness

5.24 Encouraging patients to present early with suspected skin cancer is very important. It is therefore essential to raise self awareness of how skin cancer presents to facilitate early detection. To promote this a two-pronged approach aimed at both the public and health professionals should comprise a large part of any campaign. Two recent reports would guide this. The first is the recent Cancer Reform Strategy¹⁸, which focusses on both early detection and access to high quality treatment. The second is the NICE service guidance on skin cancer, which gives a clear steer on the referral pathways for people with a possible skin cancer¹².

5.25 One of the campaign’s main aims would focus on early detection, self-checking for skin cancer and how to spot the signs of a melanoma and with user-friendly messaging. It would also advise the public on where to seek help and to whom to expect to be referred should there be any concerns.

5.26 The early detection angle would also target health professionals - from community pharmacists who are often the first port-of-call for people concerned about their skin, to GPs who refer patients into secondary care - about the importance of early detection, and the required referral pathways as outlined in the NICE guidelines.

Recommendation: A comprehensive review of skin cancer prevention should be undertaken by NICE, concentrating on the following principles:

- Providing clear and robust advice
- Including information about earlier recognition of skin cancer
- Considering whether a campaign similar to “Slip-Slop-Slap” would work in the UK
- Creating one recognised sun care awareness brand, independent of any one charity or organisation, and available to all without copyright issues...
- ...leading to a campaign that is properly resourced by Government and well-co-ordinated...
- ...and one that is patient-led or with strong patient input.

Recommendation: A central resource of suitable leaflets and posters should be available, free of charge, for health education purposes. The leaflets and posters

should include photographs and signs of each type of skin cancer and advice on how patients should check their skin

6.0 Sunbeds

6.1 Use of sunbeds increases the risk of skin cancer and, the more and earlier an individual uses one, the more that risk rises²¹⁻²³.

6.2 A report published by the International Agency for Research into Cancer (IARC) found that people who begin to use sunbeds under the age of 35 increase their risk of malignant melanoma by 75 per cent²⁴

6.3 A survey conducted by Cancer Research UK (CRUK) of 4,000 people found that 82 per cent of users first used sunbeds before they were 35 and it is clear that these people are at a greatly increased risk of developing skin cancer.

6.4 In 2007, scientists at the Ninewells Hospital & Medical School in Dundee compared current sunbed usage to a 1998 survey of sunbeds in the Dundee, Perth and Kinross areas, and also surveyed the habits and opinions of sunbed users²⁵.

6.5 Their study revealed a 30 percent increase in the number of privately operated sunbeds since 1998, despite increased warnings over the cancer dangers involved in sunbed use. This is concerning because, in the earlier study, which looked at environmental health factors, it was found that many privately operated sunbeds:

- did not attempt to impose a limit on the number of sessions (89 percent)
- provided inadequate information about use and dangers (81 percent)
- did not maintain any customer records (59 percent)
- failed to display guidance on best practice (33 percent).

6.6 The team also measured the levels of cancer-causing UV radiation created by each sunbed, and found that the majority (83 percent) produced UVB radiation levels that exceeded the European standard. Based on their study, they concluded that *'there is a strong case for regulation of sunbed operators coupled to improved patient education'*

6.7 Equally worrying is the emergence of stronger, high powered sunbeds. The earlier study found that sunbeds carried a cancer risk similar to that of UK summer sun. However, since 1998, there have been technological developments leading to new, more powerful 'fast tan' units. These have become increasingly popular, along with the emergence of unsupervised sun parlours. The average sunbed now carries the same cancer risk as the midday southern European/Mediterranean sun, whereas in the previous study this only applied to stand-up booths. This increase in carcinogenic potential is directly related to the widespread use of high power sunlamps, both in stand-up booths and lie-down sunbeds.

6.8 At present, those offering sunbed facilities can advertise what they often call "the health benefits of sunbeds", without balancing this with clear advice signalling the potential dangers. This practice must be stopped not least because allowing it to continue runs counter to other prevention messages.

HSE Advice

6.9 The Health and Safety Executive (HSE) has produced guidance, which is in the process of being updated, relating to sun beds. It recommends amongst other things that sunbeds should not be used by people who:

- are under 16 (expected to increase to 18 shortly)
- are fair skinned
- have burned regularly in the past
- have freckles or red hair
- have a history of skin cancer in their family
- are wearing perfume or deodorant.

6.10 It also recommends against too many or multi- sessions and that eye protection should be worn.

6.11 The guidance recommends that staff be trained to answer health questions relating to the above points and to give different advice to people with different skin types.

6.12 This Code is not mandatory, except in so far as there is general duty under the Health and Safety at Work Act 1974 and Regulations of 1999. The view of the APPGS is that until it is, it is unlikely that many operators will feel obliged to comply with its recommendations. Certainly the evidence of our own admittedly low level research and that of the other bodies quoted here, is that many operators are a long way away from complying with it as things stand. Ireland has recently decided to impose mandatory rules to govern sunbed use and other countries will, in due course, no doubt follow suit. Governments in the UK should consider the value of doing the same.

APPGS Field Research into Practice in Tanning Salons

6.13 The APPGS has undertaken its own research (in September 2008) to establish whether sunbed salons do comply by the HSE code of practice. This was not intended to be highly scientific but to provide a flavour of what was happening in these salons.

6.14 A researcher and a separate witness entered five salons and made enquiries about using the sunbeds. This was in order to discover whether guidelines from the HSE were being followed in a range of randomly chosen different tanning salons.

6.15 The researcher was 17 years of age and had very fair skin. She did not at any point use the sunbed.

6.16 The researcher suggested that she needed to “get a tan quickly”, with a deadline of three weeks, and asked if it was possible to book double sessions. She asked whether there was anything she needed to bring with her or needed to know before she returned. She stated clearly at each salon that she did not tan and burned very easily. She expressed concern about using the sunbeds and asked if there were any possible risks.

6.17 Both the researcher and the witness in attendance made an assessment of what advice and warnings were visible in each of the salons.

6.18 The following findings were made in all of the salons that we visited:

- A seemingly unlimited number of sessions were offered
- Tanning accelerators were offered
- High-powered tanning machines were offered
- No mention was made of the need to remove perfumes, moisturisers and other cosmetics before using the sunbeds
- The researcher was not asked her age, she was not asked for ID, nor told to bring proof of age with her when she returned
- No comment was made on the need of the researcher to take care because of her skin type
- The researcher was reassured, categorically, that there was absolutely no danger or health risk involved with using the sunbeds, despite the fact that the researcher clearly stated that she burns easily and doesn't tan
- There was insufficient advice and warnings on the risks of using sunbeds, in the form of posters or leaflets.

6.19 APPGS concludes therefore that current guidance is probably often being ignored.

6.20 We have been presented with evidence to suggest that some salons are making greater efforts than others to comply with the HSE code. We welcome this. Our view remains, however, that a mandatory code would ensure proper compliance across all salons and that this is strongly in the interests of consumers.

Recommendation: The HSE's proposed new advice should be made mandatory, including a ban on use of sunbeds by those under 18

Recommendation: Unstaffed, coin operated sunbeds should be banned unless they can provide clear proof of compliance with the HSE's advice

Recommendation: Better point-of-sale information should be mandatory where sunbeds are available, advising people of the health risks associated with sunbed use

Recommendation: All sunbed providers must be prevented from undertaking any positive healthcare advertising

Recommendation: Public bodies, such as local authority sports centres, should not be allowed to offer sunbeds, as this influences public perception that such facilities are healthy.

7.0 Early Diagnosis and Imaging Techniques

Background

7.1 This section relates to the early diagnosis of MM, which is the most dangerous but least common type of skin cancer.

7.2 The earlier that MM is diagnosed, the more likely it is that the patient will be cured. It is well recognised that the major factor that influences survival rates in patients with MM is delay both in presentation and diagnosis.

7.3 Skin cancer awareness programmes can go some way towards encouraging patients to present earlier with a suspicious mole. It is important, when patients seek advice about a pigmented lesion, that an accurate diagnosis is made as to whether the lesion is benign or malignant. The best management for the patient is ensuring that a MM is excised as quickly as possible whilst minimising unnecessary anxiety to the patient and inappropriate skin surgery. Patients need to have the best opportunity for correct diagnosis *at the outset* so that they do not become unduly alarmed and have a mole removed unnecessarily.

7.4 Various techniques, including hand-held dermoscopy, computerised dermoscopy systems and teledermoscopy, have been developed to try and improve the accurate early diagnosis of MM. These services are provided in a variety of settings by a range of health care professionals. Our Enquiry received information from a range of sources about these services and some important issues were raised

7.5 Increasingly dermatology services are becoming dominated by skin cancer and this can be at the expense of other dermatological conditions. 50% of referrals to specialists are now skin lesions²⁶. Cancer screening clinics are also receiving large numbers of benign lesions.

Dermoscopy

7.6 This technique uses illumination and magnification to enable the observer to enhance the visibility of structures in the skin lesion and provide additional information for the clinician to aid them in their diagnosis of the benign or malignant skin lesion.

7.7 We received the following evidence²⁷:

- This is an established technique used by dermatologists worldwide
- Studies have confirmed that training of both generalists and specialist doctors in dermoscopy can improve diagnostic accuracy when compared with naked eye examination only. We were not provided with any evidence about similar studies related to the training of nurses or other health care professionals
- Based on available evidence it is recommended that hand-held dermoscopy be used to augment clinical decision-making, not replace it
- Dermoscopy training has now been received by approximately 326 of the 500 dermatologists and is also widely available to interested GPs in particular through the Primary Care Dermatology Society (PCDS)¹¹
- There is a range of courses available in the UK for interested clinicians to develop the use of this technique in the context of providing an additional tool to aid in the diagnosis of MM, in addition to history examination and clinical decision-making. These include distance learning courses.

Computerised dermoscopy

7.8 These systems use digital images from dermoscopy linked to computer algorithms to separate benign from malignant lesions and to identify early MM.

7.9 According to recent independent review of the evidence, claims of increased diagnostic performance of computerised dermoscopy systems appear to show little

or no added benefit of computer-assisted diagnostic imaging techniques for the experienced dermatologist²⁷.

7.10 Furthermore, studies suggest that, when computerised dermoscopy alone is used (without the aid of a specialist), there is a tendency to over-diagnose benign lesions as potential MM, which may lead to unnecessary skin surgery²⁷.

7.11 Equally, mole mapping using digital dermoscopy images in patients with many moles and at high risk of MM, does have value in specialist dermatology clinics to help to monitor changes in pigmented lesions over time²⁷.

Teledermoscopy

7.12 This system uses dermoscopy digital images sent electronically for lesion diagnosis or second opinion.

7.13 There is evidence to support its use in this context. However, evidence typically derives from when the referring clinician is also experienced in examining the skin and diagnosing skin lesions.

7.14 A recent study showed that even in expert hands, teledermoscopy can lead to improper management of melanoma in up to 30% of patients, so should be routinely adopted only with caution²⁷.

Recommendation: Treatment guidelines must clearly highlight that, whilst all types of dermoscopy can be an invaluable additional diagnostic tool, there is currently insufficient evidence to justify its use in place of a full medical examination by a dermatologist.

High Street Mole Clinics

7.15 Evidence was received from independent providers already offering, and those planning to provide, mole screening and diagnostic services for skin cancer. Some independent providers of mole screening services are in discussions with Primary Care Commissioners and are hoping to provide mole screening services for NHS patients. It is vital that these clinics are staffed by appropriately trained clinicians.

7.16 Evidence submitted suggested that these clinics were frequently staffed with nurses who had received perhaps a week or two of training in skin lesion diagnosis²⁸. Images were taken using computerised dermoscopy. In some clinics, a computerised algorithm was used and in others images were sent for remote review by a specialist.

7.17 The panel received oral evidence that NHS dermatologists are seeing patients from these clinics who had not formally been referred on but who did actually require referral to a dermatologist. We were also told of some who had been alarmed by suggestions that they had a malignant lesion, which in fact proved to be benign.

7.18 Audit data was requested from these providers in respect of outcome measures for their services, in particular the numbers of patients seen and accurate pick up rates for melanoma. At publication of this report, this information had not been received.

7.19 In order to be as effective as possible such services should be led by a dermatologist and be an integral part of a skin cancer multi-disciplinary team (MDT). All services must have transparent clinical governance and be staffed by clinically competent professionals.

Recommendation: An acceptable level of training for clinic staff in private mole clinics must be agreed between dermatologists, clinical nurse specialists and those providing the services, to ensure quality of service provision

Recommendation: All mole clinics should run in line with NICE guidelines on skin cancer services.

NHS Mole scanning services

7.20 Evidence was received that some NHS dermatology centres are offering mole scanning services privately for income generation. These mole scanning services are advertised as 'utilising the latest mole scanning technology which monitors, and can detect, early changes in moles'.

7.21 The evidence provided questioned whether, if such services are important in the provision of optimal clinical care, they should not be available to all patients regardless of ability to pay²⁹.

Recommendation: Guidance on the role of digital imaging in primary and secondary prevention of MM and skin cancer, should be developed as soon as possible through a NICE appraisal. This should include standards for training and ongoing professional development of all those involved in mole screening

Recommendation: There needs to be clarity about the equity of access to mole screening services. If they are important and of benefit, then they should be available to all, regardless of ability to pay.

Recommendation: The same Clinical Governance frameworks, including staff training, audit and outcome measures, should be in place wherever and whoever is providing the mole screening service. This is no less important where independent providers are seeking to provide NHS services

Recommendation: The development of stand-alone NHS-commissioned mole-check services should be discouraged until further information about safety and effectiveness is available.

8.0 Generalist Care

Background

8.1 It is estimated that about 25% of consultations in primary care are primarily for a dermatological problem³⁰, yet, until recently, there has been no obligation for a GP to have had any formal undergraduate or postgraduate training in dermatology¹².

8.2 Until recently, undergraduate medical training in dermatology in the UK was typically not more than 2 weeks and in some medical schools dermatology undergraduate education was optional. The APPGS has previously reported on this¹³. Historically GP training schemes have included no more than one or two half days during the GP registrar one year training period. Many younger GPs have therefore received neither undergraduate nor post graduate training in dermatology.

8.3 There are no plans and there is no allocated funding to enable further GP education or training in dermatology for this group. New educational programmes are now gradually being introduced but the benefits will not be seen for many years. Inevitably, therefore, secondary care has to cope with a large number of referrals from those GPs who have little expertise in dermatology. This can lead to over-referral of trivial skin lesions and under-referral of potentially serious conditions.

8.4 There is, however, a large number of GPs who have developed a special interest and skill in managing dermatological conditions in primary care and have more knowledge and skills than other GPs. Membership of the PCDS is over 1,000 and a large number of UK GPs have passed the one year postgraduate Diploma in Practical Dermatology from Cardiff .

8.5 Some of these GPs are currently involved in managing patients with low risk skin cancer such as BCC. The NICE Improving Outcomes Guidance on Skin Cancer¹² recommends that suspicious lesions are referred to specialists, usually in secondary care centres. The guidance makes clear that patients with this type of skin cancer managed by GPs should expect the same standard of care - all clinicians who treat skin cancer should be a member of a skin cancer MDT and attend at least 4 meetings per year. There should be audit of adequate excisions annually and at least 40 cases should be undertaken annually by the particular clinician³¹ .

8.6 Whilst this guidance provides a framework to ensure the same standard of care is provided by whoever, and wherever, the patient is treated, it precludes many GPs from involvement in the management of any skin cancer, beyond referral.

8.7 The number of cases of MM and SCC is rising alarmingly (MM at 3-7% annually). These tumours however can be aggressive and should be managed exclusively in secondary care. Specialists have highlighted their concern that the rate of inadequate excision in primary care is unacceptable and substantially higher than in specialist hands.

8.8 Many GPs do need help with recognising these tumours, particularly as the average GP may only see a new case of melanoma every 3-4 years, although they are likely to be consulted about a pigmented lesion most weeks.

8.11 BCCs, on the other hand, are extremely common and the lifetime risk of developing a BCC is around 30%. There are more BCCs than all other cancers affecting any organ put together and the number is rising by 3% annually. Frustratingly, there is little in the way of reliable information about the incidence of BCC because, even though it is the commonest malignancy, there is no national mechanism to collect information about the number of BCCs.

8.12 These tumours virtually never metastasise and typically grow very slowly over many years. It can take up to 50 years from exposure to UV light before a BCC develops, so changes in our behaviour today, whilst clearly very important for the individual, will not impact on the problem for many decades to come. Furthermore, as this condition is substantially more common in older people, as the population lives to greater old age, the numbers will increase even faster.

8.13 Additional investment is required fully to implement the NICE guidance fully and to date, in most parts of the country, there has been no provision of additional funding to support the NICE recommendations.

Conclusions

8.14 Implementation of NICE guidance will be challenging and may result in an increase in referrals to secondary care. The specialist members of our Group firmly supported the NICE guidelines (in line also with the view presented to us from the BAD) and are confident that there is sufficient manpower in secondary care to cope with the workload.

8.15 The PCDS' view, however, is that this is not necessarily the only option for 'safe' BCCs and may not be affordable even in the near future. Models need to be developed that enable patients to receive the same standard of care for their BCC, whether provided in primary or secondary care by GPs or by specialists.

Recommendation: NICE guidance be implemented, and in particular:

- Skin lesions suggestive of MM or SCC should be referred to secondary care via the 2 week wait referral process
- Larger BCCs or those at higher risk sites should be referred to secondary care (but not via the 2 week wait process)
- Smaller nodular and superficial BCCs in safer sites can be managed in primary care by appropriately experienced and qualified GPs working within quality frameworks outlined in the guidance entitled *Guidance and Competencies for the Provision of Services Using GPs with Special Interests (GPwSIs): Dermatology and Skin Surgery* published by the DH in 2007³¹ .

9.0 Specialist Care

9.1 Specialist skin cancer services provide the following elements of patient care:

- Skin cancer screening for patients referred to secondary care
- Clinical diagnostic service (with or without dermoscopy)
- Diagnostic services – biopsy of skin lesions and sites suspicious of secondary tumour involvement, including fine needle aspiration, sentinel node biopsy and radiological investigation
- A full range of treatment options, including excisional surgery (dermatological surgery, plastic surgery and Mohs' surgery), radiotherapy, photodynamic therapy and topical immunotherapy
- Care of patients with less common tumours, for example, cutaneous lymphoma
- Histopathology services for diagnosis and review of tissue samples
- Multi-disciplinary teams (both local and specialist)
- Follow-up services.

9.2 Such services are usually provided within hospital facilities but can be provided in outreach settings linked to the specialist centre. The management of patients with skin cancer requires the collaborative input of a number of related specialties which co-ordinate their activities. In most units, the specialties involved are dermatology, plastic surgery and radiotherapy. Specialist pathology services are also essential and

other disciplines may be involved in some areas. Active collaboration, and often co-consulting, is an integral part of the patient management process. Depending upon the route of referral, investigation and treatment may be carried out by any of the specialties involved.

9.3 The NICE guidance on skin cancer lays down a structure within which those involved in managing skin cancer should practice. This guidance was developed through a multi-professional and multi-disciplinary approach. It exists to correct unacceptable variations in the quality and availability of care for patients with actual and suspected skin cancer.

9.4 The proposed structure focuses on the importance of local and specialist MDTs meeting regularly and discussing cases where patients have been diagnosed with skin cancer. The guidance also outlines the need for patients with particular types of skin cancer and their associated complications to be referred to specialist teams. MDTs are generally led by a consultant dermatologist with a special interest in skin cancer care.

9.5 The systems for delivering specialist skin cancer care, are, on the whole, well developed and easily adjusted to meet the requirements of NICE guidance. However, this requires that appropriate funding for professional and administrative support is available. Current arrangements often provide an effective basis for teaching and training, audit and research. National, multi-specialty approved guidelines exist for the care of patients with common types of skin cancer and provide a resource for management and audit.

9.6 Nonetheless, data collection remains patchy, in spite of the existence of well-developed systems. Formal assessment of clinical load and the effectiveness of individual services are often unsatisfactory. However, adequate data exists with which to establish appropriate outcomes for patients, providing benchmarks against which individual units and practitioners may compare practices. Overall, these data illustrate the effectiveness of many specialist service arrangements, particularly in contrast to less well-developed and often *ad-hoc* generalist services, where data collection, audit and research are notable for their paucity. Skin cancer co-ordinators need their job descriptions changed to require them to start collecting data on BCCs.

The Patient Pathway

9.7 Approximately 50% of the patients seen in dermatology departments are referred for the assessment of potential skin cancer²⁶. It is imperative that these patients are seen by clinicians who are trained to make accurate diagnoses at the earliest possible opportunity.

9.8 This system relies on the recognition of significant skin cancer by GPs and is generally ineffective, because of the lack of experienced GPs, noted above (see 8.4). Once referred, patients are seen for screening in face-to-face consultations.

9.9 Some units use tele-dermatology as a means of prioritising referrals and allocating them to appropriate clinics or operating lists; we have already noted above that this is not without its failings (see section 7).

Current limitations

9.10 Inconsistencies exist in the way procedures within the skin cancer pathway are coded and funded. For example, plastic surgical procedures are uniformly coded as day-case procedures (£600-£1,000), but identical procedures carried out within dermatology services will often be coded as a standard follow up appointment (£50). An urgent review of coding practice to ensure consistency of coding and reimbursement is required.

9.11 Data collection is incomplete, notably in the case of BCCs, for which only the index tumour is recorded (the first tumour with which a patient presents to the doctor), even in patients who have multiple tumours. Improvements in data collection would aid planning and enable the improvement of services.

9.12 Patient groups particularly at risk of skin cancer, such as those who are immunosuppressed, are often inadequately provided for. Specialist clinics should exist to help these groups where - ideally - clinicians work together to provide jointly staffed clinics that provide specialist diagnosis and treatment e.g: renal and dermatology consultants holding clinics for people who have had a transplant and are at risk of developing a skin cancer. NICE makes clear that these services should exist, but additional funding is needed to implement the delivery of this service.

9.13 The patterns of referrals to skin cancer clinics highlight the lack of training in skin cancer diagnosis in primary care. At least 10 patients with benign skin lesions are seen for every skin cancer. Many of the referrals are for benign disease. Approximately 50% of all referrals to dermatology are for skin cancer screening. With an educational programme concentrating on recognising benign cases that are presented in primary care, overall referral numbers could be reduced significantly

9.14 There is currently limited availability of Mohs' surgery which adversely affects patient care. This is a special form of surgery for a particular type of troublesome BCC. All regions should have a dermatological surgeon trained and experienced in this technique so that the most appropriate treatment can be provided¹.

9.15 Lack of compliance with NICE guidance is still common. Whilst for some individuals, this is simply a case of lack of documentary compliance, for others, it conceals a lack of appropriate training and skills. This issue needs to be addressed. It is recommended that the involvement of enthusiastic amateurs should be avoided. However, the involvement of appropriately skilled individuals from all areas of clinical practice should be encouraged by appropriate accreditation, inclusion in the MDT process, data collection and audit.

Recommendation: An urgent review of current coding practice is required

Recommendation: Data collection should be improved

Recommendation: Investment in the specialist clinics is required, as advised by NICE, for people at particular risk of skin cancer, such as organ transplant recipients

Recommendation: There should be greater focus within pre and post graduate medical education on the recognition of all lesions

Recommendation: All regions should have a dermatological surgeon trained in Mohs' surgery

Recommendation: Clinicians of any sort who lack the appropriate training and skills to diagnose and treat skin cancer or its consequences, should not be involved in its

management. Support and training should be offered before such a service should be allowed to continue, by the responsible PCT.

10.0 Pharmacy in Primary Care

10.1 The community pharmacist has been referred to as the healthcare professional on the high street. This accessibility means that the pharmacist is ideally placed to offer advice and information to patients. Such information could include advice regarding appropriate use of sunscreens and referral to GPs for any patients who notice changes in their moles or those with suspicious lesions.

10.2 However, in common with other healthcare professionals, pharmacists receive little formal training in dermatology. The Centre for Postgraduate Pharmacy Education has recently updated a training package (available free) on managing skin conditions and is in the process of developing an on-line course for pharmacists with a special interest in dermatology. Unfortunately, however, neither package contains any information on skin cancers or recognition of suspicious lesions.

10.3 The APPGS heard evidence of the potential to set up mole clinics in pharmacies. These services have already been established in some community pharmacies and may involve a specialist nurse trained in dermoscopy. Such services are usually not free, however, and continuation and further development would require commissioning by the NHS and a real emphasis on training and skills of those involved in delivering such a service and links with appropriate specialists.

10.4 Community pharmacists should be part of the primary care MDT and skin cancer (eg mole recognition/monitoring) services based in community pharmacies need to be integrated with multi-disciplinary primary care dermatology services.

10.5 One option would be for large community pharmacies to provide consulting rooms for other members of the MDT on a sessional basis, as has happened with other specialties.

10.6 The development of accredited Pharmacists with a Special Interest (PhwSI) may support this. A framework for PhwSI in dermatology has been developed and pharmacists should be encouraged (or incentivised) to take this option up and to seek accreditation³².

10.7 Pharmacists might sensibly be integrated into public health campaigns, reinforcing messages about covering up, avoiding unnecessary UV exposure and advising on sun screens.

10.8 They also have a part to play in identifying and advising immunosuppressed patients who need additional UV protection, reinforcing advice received elsewhere. Some drugs also make people more UV sensitive and therefore susceptible to burning. Pharmacists have a logical role to play helping here.

Recommendation: The APPGS recommends that, in line with other healthcare professionals who are in contact with patients with potential skin cancer, pharmacists should receive further training in the identification of suspicious lesions, so that a patient pathway can be established

Recommendation: Pharmacists should be encouraged (or incentivised) to take up PhwSI training and to seek accreditation.

11.0 Models of Care: Integration of generalist and specialist services

The importance of integrating services

11.1 The integration of generalist (primary) and specialist (secondary) care services to optimise care for patients with skin disease is well documented²⁶. The recently published 'Shifting Care Closer to Home: Dermatology Specific Recommendations' states that '*there must be seamless timely access to specialist diagnostic skills as and when needed.*'

Integrating services to ensure rapid access to diagnosis of skin cancer

11.2 NICE guidance¹², makes clear the need for the development of uniform standards of care for patients with suspected and diagnosed skin cancer across cancer networks, wherever and whomsoever provides the care. The separation of diagnosis and management for skin lesions was recommended in the AOPS Good Practice Guidance²⁶, to ensure the timely management of skin cancer and unnecessary skin surgery. This approach is supported by NICE, which specifies the need for all suspicious skin lesions to be referred to a specialist (usually a dermatologist).

11.3 To support the implementation of the above, several processes and tools exist²⁶. These include:

- The DH 2 week wait suspected skin cancer referral service
- The 31/62 day cancer diagnosis and treatment targets
- The 18 week referral to definitive treatment target supported by the 18 week skin lesion pathway,
- The AOPS skin lesion model and
- The use of the commissioning cycle and the new guidance '*Providing care for patients with skin disease: guidance and resources for commissioners*³³.

11.4 The commissioning cycle provides the framework for the development of integrated patient-centred services with uniform standards of care and is ideally suited to the development of skin cancer diagnosis and treatment services. Pivotal to the implementation of the NICE guidance is the development and implementation of skin cancer multidisciplinary teams (local and specialist). This brings together generalists with additional accredited skills in skin cancer management³¹ with specialists and other members of the wider clinical team, to discuss the care of all patients with skin cancer in the local health community.

11.5 The guidance documents entitled *Implementing Care Closer to Home: providing convenient quality care for patients (Parts 1-3)* and the specific guidance for dermatology and skin surgery^{26,31}, offer further support for the development, accreditation and implementation of services that cross the primary/secondary generalist/specialist interface.

Evidence for integrating services/joined up pathways of care

Recurring Issues

11.6 Toolkits exist to deliver joined up seamless care³³. However, implementation is patchy. Commissioning skin cancer services is inconsistent, often inadequate and needs strengthening to meet agreed national guidance and quality frameworks. For example, a skin cancer service has been commissioned in Nottingham that is not integrated with the local skin cancer services MDT³⁴. This creates a service that does not meet the NICE guidelines and may put patients at risk due to a lack of shared knowledge and continuity at this stage of the patient journey.

11.7 There are examples of good practice but working in isolation. For example, also in Nottingham, there is an excellent skin cancer service providing rapid access to diagnosis and management³⁵. It meets national guidance but is not linked to the community cancer service that has been commissioned.

11.8 The current payments system, including the Payments by Results tariff and the consequences for the implied cost-per-case, has led to a disincentive for Primary Care Clinicians to refer patients to specialists for diagnosis and treatment. The incentive is now to reduce spend on specialist services. In the last 2 years, 80% of PCTs have commissioned 30%-50% fewer secondary care appointments this year making many hospital departments financially unstable (SCC 2008).

11.9 Getting GPs involved in local skin cancer MDTs to integrate care and improve links has proved very challenging, as there are considerable time and cost barriers that need to be overcome.

11.10 Training and accreditation of Group 3 GPwSI Community Cancer Clinicians is expensive for PCTs and a disincentive to the process. We believe that the best possible service would be provided by outreach cancer services provided by the local MDT, where governance frameworks and training are well established.

11.11 Evidence from one pharmacy group³⁶ caused the Group concern, as there appear to be proposals to bid to deliver NHS-commissioned mole-check services, which will operate separately from local dermatology services. As described earlier, the ideal service is a fully integrated MDT that monitors each patient from diagnosis to treatment and follow-up. Any NHS-paid-for skin cancer service must be led by a dermatologist and follow the NICE guidelines. We were not made aware of any private mole screening service being a part of any skin cancer MDT.

Recommendation: National guidance should be implemented and commissioning strengthened by better use of the commissioning cycle to develop skin cancer services locally, leading to better integration of services

Recommendation: There should be built-in flexibility around the new tariff, which was introduced for dermatology in April 2008. It should be used to facilitate the development of innovative models of care to provide integration, best value, timely access and quality care. This could include rapid access, specialist outreach skin lesion diagnosis service supported by appropriate cost-effective models of delivering skin surgery services

Holistic Treatment

11.12 In addition to the clinical recommendations for improved treatments within this report there is also a need to improve the holistic care each patient receives. Currently it is extremely rare to have any professional psychosocial input into skin cancer MDTs.

11.13 It is recognised that with all cancers each patient has different holistic needs and different levels of clinical, psychological, spiritual, financial and social needs related to their cancer, treatment and prognosis.

Recommendation: An integral part of a successful MDT must be the ability to provide or refer patients to specialist holistic providers. It should be recognised that patients whose treatment is not successful will also require the input of a specialist palliative care service

Recommendation: There should be access to lymphoedema support services for patients with skin cancer

Recommendation: Psychological and quality of life issues may require greater consideration in patients having treatment for skin cancers. Support for patients can be given by the specialist skin cancer nurse but occasionally specialist psychological referral may be needed and should be available when required

Recommendation: It should be recognised that patients whose treatment is not successful will also require the input of a specialist supportive and palliative care team

Recommendation: All patients must be able to access photodynamic therapy (PDT) if clinically appropriate.

12.0 Skin Cancer Clinical Nurse Specialists

12.1 Skin cancer is the most common cancer in the UK but has one of the lowest numbers of clinical nurse specialists. Data from the British Association of Skin Cancer Nurse Specialists shows that in 2008 there are approximately 56 dedicated skin cancer nurse specialists within the UK. Compared with the number of dermatology units (approximately 220), it can be seen that many people with skin cancer will not have access to the care that skin cancer nurse specialists provide.

12.2 The NICE guidelines recommend that every skin cancer multi-disciplinary team should have a skin cancer clinical nurse specialist and that they “should 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”. The follow-up service provided by the nurse allows the doctor to see those new patients who are referred via the 2-week rapid access skin cancer clinics, ensuring that all patients with suspected SCC or MM are seen in a timely manner. This will also allow the service to cater for what is expected to be a continual rise in patients being referred with skin cancer. However, without more funds, many departments are struggling to meet these guidelines.

12.3 The role of the skin cancer clinical nurse specialist (CNS) is to manage, support and inform patients, families and carers through their skin cancer journey, providing practical help, emotional and psychological support. The CNS has responsibility for

sun-awareness, health education and skin cancer prevention initiatives, often with a limited or non-existent budget. The CNS is tasked with running campaigns designed to reach all those at risk. Prevention campaigns are vital if the current trend of a year-on-year increase in prevalence of skin cancer is to be reversed. Many nurses have to write and produce their own leaflets and posters due to the lack of suitable, nationally available material.

12.4 The role of the skin cancer nurse specialist is different from many other specialist nurse roles, as the nurse is involved with the whole of the skin cancer journey. Many CNSs work within a team of nurses, each working on a specific part of the care pathway. The skin cancer nurse is usually the only CNS on the team and is involved from pre-diagnosis, through to diagnosis and treatment and on to discharge or death. They also cover both primary and secondary care. The CNS has to work autonomously and will usually have their own caseload of patients who cover all the age groups from children to pensioners. As with all CNSs, the nurse is solely accountable for the actions he/she takes and the care he/she provides. A recent study, based on National Cancer Data, showed that the average caseload of the skin cancer nurse specialist is 533 patients, compared with urology (131), lung (122), upper GI (98) and breast (79).

12.5 The CNS is expected to develop services and pathways that are patient-centred and is usually the lead person responsible for providing patient information and facilitating user involvement in the service.

12.6 The skin cancer CNS is involved in the care of the skin cancer patient at every step on the pathway. The skin cancer CNS, working within a cancer MDT, may perform the following roles:

- Running health education campaigns in primary care
- Triaging patients when they attend for skin cancer screening
- Performing biopsies to obtain a diagnosis under the direction of the specialist
- Giving patient their diagnosis
- Supporting patients and their families after diagnosis
- Providing both verbal and written information at each stage of the care pathway
- Administering treatment such as photodynamic therapy, excision of skin cancer
- Prescribing relevant topical medication for the treatment of precancerous lesions
- Where appropriate, undertaking the following up of skin cancer patients
- Undertaking clinics for transplant patients, to monitor their skin for skin cancers and to give education
- Educating all skin cancer patients on how to check their skin and recognise signs of skin cancer
- Liaising with other departments regarding tests and treatments
- Acting as patient advocate
- Being a core member of the skin cancer team
- Undertaking research and audits
- Teaching other health professionals and develops educational modules for universities and other educational institutions
- Supervising medical students
- Publishing articles and lecturing on skin cancer and related subjects.

12.7 These roles require nurses to be trained to a high level and to have a high level of clinical knowledge on all aspects of skin cancer, communication, nursing assessment and counselling. They will have been extensively training to undertake the role and will work to the expert level of the knowledge and skills framework.

12.8 As with most patients diagnosed with cancer, those with MM need support and counselling from the CNS to help deal with the psychological, spiritual, social and physical aspects associated with what, in 10% of cases, will be a terminal disease. The CNS helps the patient deal with issues surrounding body image, self esteem, social care and their relationships as well as preparing them for the progression of the disease and the ensuing treatments. Support is often required by their families too, and may continue even after the patient has died.

12.9 Skin cancer clinical nurse specialists are under increasing pressure as the incidence of skin cancer rises and at present there is little psychological, clinical or practical support for the nurses to help them deal with this pressure. All members of the MDT should have access to supportive clinical supervision and have their support needs addressed at each appraisal.

Recommendation: Each Dermatology unit should have a CNS in Skin Cancer at a ratio of 1 full-time employee per 160,000 population. Without this the NICE model cannot, by definition work properly

Recommendation: National guidelines, similar to those for GPwSIs, need to be developed outlining the training and experience required to become a CNS

Recommendation: Skin cancer nurse services should be expanded to allow them to contribute more widely within the MDT where their training allows this to happen

Recommendation: All members of the MDT should have access to supportive clinical supervision.

13.0 Appendices

Appendix I. Specialist Advisory Panel

Nina Goad - British Association of Dermatologists and Sun Awareness Campaign
Gill Godsell OBE, MSc, RN - Skin Cancer Nurse Specialist, Nottingham University Hospital Trust
Dr Mark Goodfield – President, British Association of Dermatologists
Andrew Langford, Chairman - Chief Executive, Skin Care Campaign
Dr George Moncrieff GP - Primary Care Dermatology Society
Dr Julia K Schofield - Principal Lecturer Dermatology, Postgraduate Medical School University of Hertfordshire; Consultant Dermatologist, United Lincolnshire Hospitals NHS Trust
Rod Tucker - pharmacist with a special interest in dermatology.

Appendix II. References

1. Written evidence from British Association of Dermatologists
2. Evidence from parliamentary written answers. Data also available from the Office of National Statistics
3. Written evidence from SKCIN – The Karen Clifford Skin Cancer Charity. Based on *Trends in incidence of skin basal cell carcinoma. Additional evidence from a UK primary care database study*. Bath-Hextall F, Leonardi-Bee J, Smith C, Meal A, Hubbard R. International Journal of cancer 2007 Nov 1st;121(9):2105-8
4. Sunsmart campaign literature
5. Written evidence and website material from Cancer Research UK. Statistical Information based on *Statistical Information Team Cancer Research UK. Information Resource Centre, 2005*
6. Cervical cancer prevalence data from:
<http://www.cancerhelp.org.uk/help/default.asp?page=138>
7. Oral evidence from Professor Moseley based on *Quantitative risk assessment of sun beds: impact of new high powered lamps*. Oliver H Ferguson J Moseley H BJ Derm 2007;157:350-360
8. Written evidence from Marc's line
9. Written evidence, Teenage Cancer Trust
10. Oral evidence, consensus from many witnesses
11. Written evidence from Primary Care Dermatology
12. *NICE Improving Outcomes for People with Skin Tumours including Melanoma: the Manual*. London: NICE (2006)
13. *Report on dermatological training for health professionals. APPGS London 2004*
14. *The Evolving Role of the Macmillan Nurse*. Webber J (1993). London, Cancer Relief MacMillan Fund
15. Oral evidence from Cancer Research UK
16. Oral evidence from a range of health care professionals
17. Information from: <http://www.cancerscreening.nhs.uk/cervical/#cost>
18. Cancer Reform Strategy DH London 2007
19. Written evidence from Killing Cancer
20. *Has mortality from melanoma stopped rising in Australia? Analysis of trends between 1931 and 1994* Giles et al, British medical Journal 1996;312:1121-1125

21. *Cutaneous malignant melanoma and exposure to sunlamps and sunbeds: a descriptive study in Belgium.* Autier P, Joarlette M, Lejeune F, Lienard D, Andre J, Achten G. *Melanoma Research* 1991; 1: 69-74
22. *Risk of cutaneous malignant melanoma in relation to use of sunbeds: further evidence for UV-A carcinogenicity* J Westerdahl, C Ingvar, A Måsbäck, N Jonsson and H Olsson. *British Journal of Cancer* (2000) 82, 1593–1599
23. <http://www.bad.org.uk/public/skin/sunbeds/> for further references
24. *The association of use of sunbeds with cutaneous malignant melanoma and other skin cancers: A systematic review.* International Agency for Research on Cancer Working Group on artificial ultraviolet (UV) light and skin cancer. *International Journal of Cancer.* 2007 Jun 1;120(11):2526
25. *Quantitative risk assessment of sunbeds: impact of new high power lamps* H. Oliver, J. Ferguson and H. Moseley *British Journal of Dermatology*, Vol. 157 Issue 2 Page 350-356 August 2007
26. Written evidence Julia Schofield
27. Written and oral evidence Jonathan Bowling. Written evidence provides further references of original articles
28. Oral evidence
29. Written evidence Ray Jobling
30. *'Dermatology: Health Care Needs Assessment : The Epidemiologically Based Needs Assessment Reviews, Second Series'*, Professor Hywel Williams. Published by Radcliffe Medical Publishing
31. Department of Health (2007) *Guidance and Competencies for the Provision of Services Using GPs with Special Interests (GPwSIs): Dermatology and Skin Surgery.* London: Department of Health
http://www.pcc.nhs.uk/uploads/pwisis/gpwisis_dermatology.pdf
32. *Implementing care closer to home-providing convenient quality care for patients. A national framework for Pharmacists with a Special Interest* DH 2007
33. *Providing care for patients with skin conditions : guidance and resources for commissioners.* Primary Care Contracting July 2008.
<http://www.pcc.nhs.uk/uploads/dermatologyguidance.pdf>
34. Written evidence Neill Shroff
35. Written evidence Gill Godsell
36. Written and oral evidence Lloyds pharmacy

Appendix III. List of Oral Evidence

Oral Evidence - 28th February 2008

Professor James Ferguson - Photobiology Unit, Ninewells Hospital, Dundee
 Dr Stephen Hayes - Primary Care Dermatology Society
 Tracy Hung - Macmillan Skin Cancer Specialist Nurse
 Professor Irene Leigh- Head of CRUK Skin Tumour Laboratory, Dundee Medical School
 Iain Mack - MD of SCanSol Ltd and The MOLE Clinic
 Neil Shroff - Partner GP, Keyworth Health Centre, Nottingham, and Karen Clifford Skin Cancer Charity
 Dr David Shuttleworth - Vice-President, British Association of Dermatologists
 Dr David Slater - President, British Society of Dermatopathology

Oral Evidence - 12th March 2008

Ms Jo Allum - MARCS Line, Wessex Cancer Trust
Ms Kathy Banks - Chief Executive, The Sunbed Association
Dr Jonathan Bowling - Consultant Dermatologist, Oxford Radcliffe Hospital
NHS Trust
Ms Linda Burt - MARCS Line, Wessex Cancer Trust
Mr Martin Crisp - Head of Pharmacy, Superdrug
Mr Chris Frost - Head of Marketing, Lloyds Pharmacy
Ms Denise Hancock - Clinical Nurse Specialist in Skin Cancer, Southampton General Hospital
Professor Eugene Healy - Professor of Molecular Dermatology, University of Southampton
Dr David Longman - Director, KILLING Cancer
Dr Harry Moseley - Head of Scientific Services for the Photobiology Unit, Ninewells Hospital
Sarah Woolnough - SunSmart Campaign Manager, Cancer Research UK

Appendix IV. List of Written Evidence

British Association of Dermatologists
Dr. Maureen Baker CBE DM FRCGP, Honorary Secretary of Council, Royal College of General Practitioners
Cancer Research UK
Richard Clifford, Secretary and Trustee, Southampton UHT
Dr. Bruce Gee, Dermatology Department, Warwick Hospital
Gill Godsell, Skin Cancer Nurse Specialist
Deidre Doogan, Lloyds Pharmacy
Merseyside and Cheshire Cancer Network
Dr Jim Hamilton, GP with an interest in minor surgery
Dr Stephen Hayes, Primary Care Dermatology Society
Ray Jobling, Chairman, Psoriasis Association
David Longman, Director, KILLING Cancer
Iain Mack, ScanCol and The Mole Clinic
Dr G C Moncrieff, GPSI in dermatology, Bicester Health Centre
Dr Barry Powell, National Clinical Lead in Skin Cancer, Department of Health
Dr David Slater, Chair of the Royal College of Pathologists Joint Sub-committee on Dermatopathology (Joint submission from the Royal Society of Pathologists/British Association of Dermopathology)
Dr Julia Schofield
Dr Neil Shroff, Bsc. MBBS, AFRCSEd., Diploma in Clinical Dermatology – St. Barts and the London; GP in Keyworth, Nottingham; part-time dermatological surgeon at King's Mill Hospital in Mansfield (Joint submission)
The Sunbed Association
Teenage Cancer Trust
Professor Pat Troop, Chief Executive, Health Protection Agency
Dr. Sandeep Varma, Consultant Dermatologist and Dermatological Surgeon, Queens Medical Centre, Nottingham; Chairman and Trustee of SKCIN – The Karen Clifford Skin Cancer Charity
Wessex Cancer Trust/Marc's Line
Catherine Wheelhouse, Clinical Nurse Specialist in Skin Cancer

Appendix V. Index of previous APPGS Reports

1. An Investigation into the Adequacy of Service Provision and Treatments for Patients with Skin Diseases in the UK (March 1997)
2. Enquiry into the Training of Healthcare Professionals who come into contact with Skin Diseases (July 1998)
3. Enquiry into Fraudulent Practice in the Treatment of Skin Disease (December 1999)
4. Enquiry into Skin Diseases in Elderly People (November 2000)
5. Enquiry into Primary Care Dermatology Services (April 2002)
6. Enquiry into the Treatment, Management and Prevention of Skin Cancer (January 2003)
7. Enquiry into the Impact of Skin Diseases on People's Lives (July 2003)
8. Dermatological Training for Health Professionals (August 2004)
9. Enquiry into the Adequacy and Equity of Dermatology Services in the United Kingdom (March 2006)
10. Enquiry into Practice-Based Commissioning of Services for People with Skin Conditions (May 2008)

Appendix VI. Officers of the APPGS

1. Rt Hon Bruce George MP, Chair, APPGS
2. Frank Cook MP, Vice-Chair, APPGS
3. Cheryl Gillan MP, Vice-Chair, APPGS
4. The Baroness Masham of Ilton, DL, Vice-Chair, APPGS
5. The Lord Henley, Treasurer, APPGS
6. Paul Burstow MP, Secretary, APPGS



All Party Parliamentary Group on Skin

St James House, 13 Kensington Square, London W7 5HD Tel: +44 (0) 20 7368 3103 Fax: +44 (0) 20 7368 3101