



SKIN CANCER REVEALED



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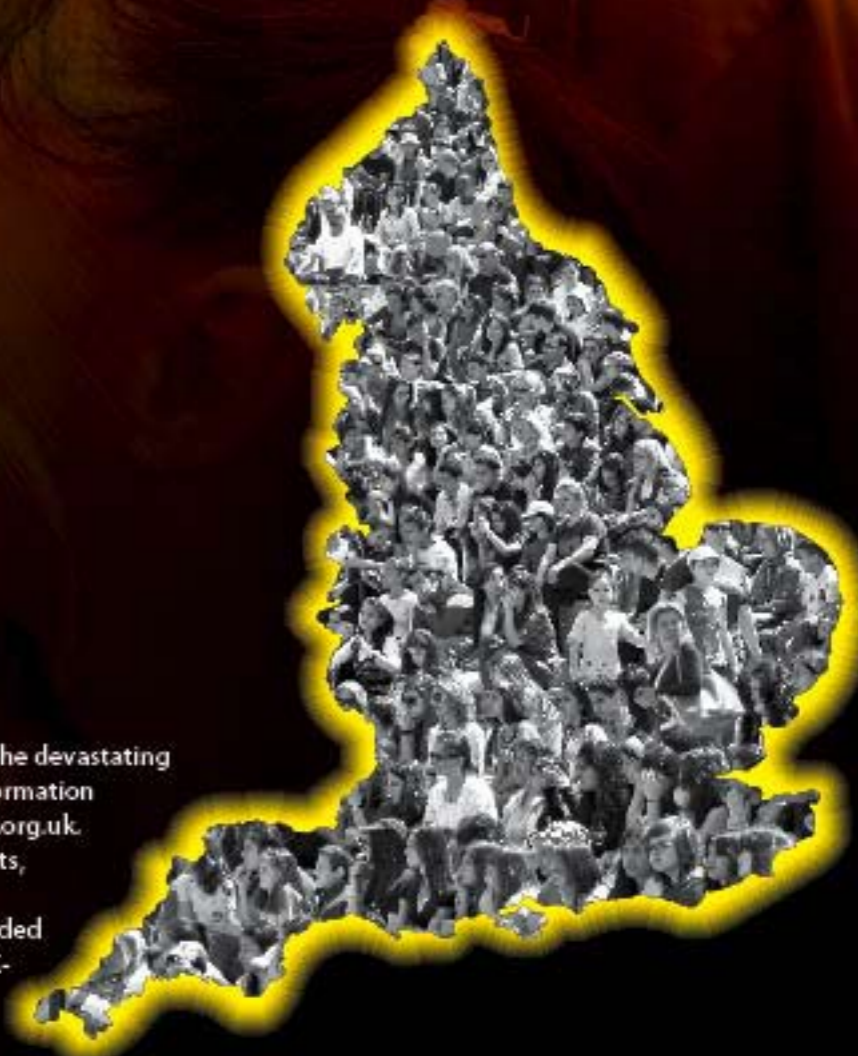
ABOUT SKIN CANCER UK

Skin Cancer UK is a coalition of professional groups and charities, including:

- SKCIN (Karen Clifford Skin Cancer Charity)
- British Dermatology Nursing Group- skin cancer sub-group
- BASCSN (British Association of Skin Cancer Specialist Nurses)



Our goal is to work collaboratively to reduce the devastating impact of skin cancer in the UK. For more information about Skin Cancer UK, please visit www.skcin.org.uk. Our first report Skin Cancer in the UK: The Facts, initiated and supported by the All Party Parliamentary Group on Skin can be downloaded from: [http://www.skcin.org/Documents/SCUK-DOWNLOAD-VERSION-\(1\)](http://www.skcin.org/Documents/SCUK-DOWNLOAD-VERSION-(1))



INTRODUCTION

Every day, more than two young adults (aged 15-34) in the UK are diagnosed with malignant melanoma – the rarest, but most dangerous, form of skin cancer. In the over 65 age-group, death rates from the disease have almost tripled in the last 30 years, and it has been estimated that overall cases of melanoma will rise by 52% by 2030 – the biggest projected increase for any form of cancer¹. While most forms of skin cancer are treatable and pose only a small threat to life, melanoma is much harder to treat unless it is detected early. It affects all ages, and every part of society, killing over 2,000 people annually².

Unlike other forms of cancer, we understand the primary cause of skin cancer, and how we can best prevent it. As incidence rates for men and women have increased at a faster rate³, year on year, campaigners have worked hard to transform the public's understanding of (and response to) the dangers of over-exposure to ultraviolet (UV), and to the signs and symptoms of skin cancer. We need to do much more to minimise the incidence of skin cancer, and to improve survival rates⁴.

Skin Cancer UK has consistently highlighted the importance of prevention and the need for greater public awareness of the risks associated with over-exposure to UV light to help encourage behavioural change and reduce the growing rate of skin cancer incidence in the UK. However, more must also be done to improve the services available to patients at every stage of the pathway, ensuring that those patients who do develop more advanced forms of skin cancer receive high quality treatment and care whilst also doing everything we can to prevent skin cancer or diagnose it early.

The good news is that the diagnosis, treatment and care of people with all forms of cancer has improved significantly over the last 15 years. However, the management of

malignant melanoma presents unique challenges for commissioners and clinicians alike. In the context of sweeping NHS change, and financial constraint, we need to redouble our efforts to tackle the devastating effects of melanoma.

The NHS reforms in England present a range of opportunities: ring-fenced resources for health protection and awareness through a new public health service, a greater role for clinicians in the way that services are run, a new focus on outcomes through *Improving Outcomes: a strategy for cancer (the IOSC)*, a Cancer Drugs Fund to ensure that patients with advanced cancer can get timely access to new treatments their doctors think will benefit them and better information to inform patient choice, enable strong commissioning and empower clinicians to make changes to improve outcomes.

There are, however, also significant challenges. Changes to NHS structures may destabilise delivery, financial constraints mean we need to do more with less, and rising incidence and prevalence will place services under increased pressure. If we are to overcome these challenges, then the NHS needs to become better at learning from examples of good practice, raising the overall quality and consistency of skin cancer services and identifying opportunities for realising efficiencies which improve the quality of care rather than diminishing it.

Accurate and timely information will be critical to achieving this. Recent improvements in cancer intelligence have revealed new patterns in skin cancer delivery. We need to act on these findings to improve outcomes. This report – *Skin Cancer Revealed* – provides the most comprehensive summary of information on patterns in skin cancer incidence and outcomes, as well as service delivery, to date. It is intended to:

- Bring together disparate sources of information to support policymakers and others who are interested in tackling skin cancer
- Prompt discussion and debate about variations in skin cancer delivery and outcomes
- Provide a baseline assessment against which progress can be assessed

Skin Cancer UK is a coalition of professional groups and charities working collaboratively to reduce the devastating impact of skin cancer in the UK. This means:

1. Achieving a measurable reduction in the number of new cases of malignant melanoma every year through improved education and changing patterns of behaviour
2. Delivering high quality information, treatment, care and support at every step of the patient journey
3. Improving the outcomes and experiences of patients living with skin cancer, regardless of the stage of the disease

Our first report, *Skin Cancer in the UK: The Facts*, commissioned by the All-Party Parliamentary Group on Skin, addressed the first of these goals and called for a well-funded, national public awareness campaign, alongside a focus on sun education and protection in schools. This latest report, *Skin Cancer Revealed*, is an important step towards delivering on all three objectives in England.



How information is critical to high quality services

Service quality
• Peer Review
• Cancer Drugs Fund

Population needs
• Incidence
• Prevalence
• Mortality
• Years of life lost

HIGH QUALITY SERVICES

Expenditure
• Programme budgeting
• Length of stay
• Diagnostic investigations

Patient-level data
• Stage and type of cancer
• Patient Experience



RECOMMENDATIONS

Recommendation 1: Public Health England (PHE) should develop a strategy to ensure the delivery of consistent public health messaging on sun safety and the dangers of over-exposure to UV at a national and local level

Recommendation 2: Interventions should be targeted at high risk groups including deprived communities and men to increase awareness of the signs and symptoms of melanoma and encourage them to present earlier to their GP

Recommendation 3: Initiatives to raise awareness of the signs and symptoms of melanoma must be properly evaluated by the Cabinet Office's Behavioural Insight Team to better understand the interventions which drive behaviour change, and good practice examples should be disseminated to local services via the National Awareness and Early Diagnosis Initiative (NAEDI)

Recommendation 4: The Department of Health and Public Health England should develop joint commissioning indicators for skin cancer

Recommendation 5: Commissioners should ensure that providers adhere to agreed standards on cancer waiting times for patients with malignant melanoma, including the two-week urgent referral pathway, and two months wait from urgent referral to treatment

Recommendation 6: NICE should review new treatments for advanced melanoma using the agreed criteria for end of life treatments

Recommendation 7: Clinical Commissioning Groups should ensure that patients can access treatments that are recommended by NICE in line with the NHS Constitution and patients should be able to appeal to the NHS Commissioning Board when this duty is not upheld

Recommendation 8: Cancer Drugs Fund clinical panels should regularly review the evidence for the inclusion of new treatments for melanoma, so that clinicians can access the treatments they feel will benefit their patients in a timely way

Recommendation 9: The NHS Commissioning Board should develop a commissioning plan to support the delivery of effective molecular diagnostic testing through centres of excellence

Recommendation 10: Providers should where possible follow the principles of the enhanced recovery

programme to improve the experiences and outcomes of patients, and improve the efficiency of surgery

Recommendation 11: Clinical Commissioning Groups should ensure that they plan capacity effectively to accommodate an increase in demand for services, including the support of multi-disciplinary teams (MDTs) to provide high quality expert input to the treatment and care of all skin cancer patients

Recommendation 12: All providers should critically appraise the findings of the National Cancer Patient Experience Survey and act to address any weaknesses identified. Verbatim feedback should be used to add colour to numerical findings

Recommendation 13: Commissioners should use the information in the National Cancer Patient Experience Survey as the basis for incentivising providers to improve the quality of care they deliver through the CQUIN framework

Recommendation 14: Commissioners reporting a significant fluctuation in expenditure on skin cancer should critically appraise the reasons for this and should publish explanations in their annual reports

Recommendation 15: Commissioners which are outliers in terms of reported expenditure should assess whether the level of funding they are allocating to skin cancer is appropriate

Recommendation 16: NICE should develop the proposed quality standard on skin cancer as a priority and should consider developing a dedicated quality standard on malignant melanoma

Recommendation 17: The Public Health and NHS Outcomes Frameworks for 2011-12 should include measures to improve outcomes in skin cancer covering prevention, early detection and effective treatment and management

Recommendation 18: A range of incentives should be developed to support commissioners in improving the quality of care for skin cancer

Recommendation 19: Cancer networks should provide expert advice to commissioners. In order to ensure that appropriate advice is available on skin cancer, networks should include melanoma specific reference groups

KEY FINDINGS

Incidence

- There is an almost eight-fold variation in incidence of malignant melanoma between PCTs in England. NHS Plymouth had the highest incidence rate (28.7 cases per 100,000) between 2006 and 08 compared to NHS Newham in London which had the lowest incidence rate (3.69 cases per 100,000).

- Over two thirds (70%) of the PCTs with malignant melanoma incidence rates in the highest 20% of the country were in NHS South demonstrating the burden of melanoma for this area of the country. 70% of the PCTs with the lowest incidence were in NHS London.

- Asian and Black populations are at a significantly lower risk of developing melanoma⁶. This is because people with naturally brown or black skin have more melanin pigment in their skin cells which can protect the skin from UV damage⁷. NHS Newham and NHS Heart of Birmingham, which both had lowest incidence rates for malignant melanoma in the country in 2006-2008, also had the lowest percentage of white population. Conversely, those PCTs with the top ten highest incidence rates had a white population of over 90%.

- Melanoma is associated with affluence. Although the association with affluence has diminished in recent years, it is still notable. NHS Newham has one of the highest deprivation scores and the lowest incidence rates whilst the converse is true for NHS Oxfordshire. However, high levels of incidence are observed in some deprived areas. For example, NHS Blackpool, NHS Liverpool, NHS Knowsley, NHS Salford and NHS Blackburn with Darwen Care Trust, which were all in the top 20% most deprived areas in the country, also had above average incidence rates for melanoma^{8,9}.

Outcomes

- NHS London, which had one of the lowest incidence rates for malignant melanoma in 2008, also had the second poorest survival rate for melanoma patients diagnosed between 2000-2004, with 83.8% of patients alive five years after diagnosis. Survival was lowest in NHS South East Coast (82.9%) and NHS South Central had the highest survival rates for this period (90.4%).

- Patients diagnosed at early stage disease (stage 1A), have a good prognosis with five year survival at 95%¹⁰. However, a fifth of patients are diagnosed with advanced disease¹¹ when melanomas have spread to nearby lymph nodes (stage 3) or other elsewhere in the body (stage 4) such as the lungs, liver or brain or to distant lymph nodes or areas of the skin. The outlook for patients diagnosed with advanced stage disease is much poorer¹².

- The proportion of patients diagnosed following an emergency presentation was lower for skin cancer (3%) than any other cancer¹³. This is encouraging given that one year survival for skin cancer patients diagnosed as an emergency is 61% compared to 97% for diagnosis through all other routes¹⁴.

Treatment and care

- All patients being treated at Norfolk and Norwich University Hospitals NHS Foundation Trust and Salisbury NHS Foundation Trust reported seeing their GP just once or twice before being referred to the hospital, while 17% of patients at the University Hospital Birmingham NHS Foundation Trust had seen their GP more than twice before being referred¹⁵.

- While the majority of patients do see a hospital doctor within four weeks, in three Trusts where data for skin cancer patients are available (County Durham and Darlington NHS Foundation Trust, North Bristol NHS Trust and Plymouth Hospital NHS Trust), one in five patients had waited more than a month to attend an appointment¹⁶. 61% of patients who said they had seen their GP said they waited two weeks or less before their first appointment with a hospital doctor.

- Many skin multi-disciplinary teams (MDTs) are in an early stage of development, and inadequate MDT membership and attendance have affected the majority of teams in some way. A majority of MDTs were unable to show that they were continuously improving their service including both clinical effectiveness and the patient experience¹⁷.

- 75% of melanoma patients who took part in the National Cancer Patient Experience Survey reported that they were given the name of a clinical nurse specialist who would be in charge of their care, below the average for all tumour types¹⁸.

- Only 60% of skin cancer patients were told they could bring a family member or friend with them when they were first told that they had cancer, the lowest of all tumour types¹⁹.

- The relatively low approval rates for treatments through the Cancer Drugs Fund in the south of England is concerning²⁰, given the higher rates of melanoma incidence and mortality in these parts of the country. It will be important for local clinical panels to respond effectively to the growing needs of melanoma patients with advanced disease in their region.

Expenditure

- Information reported by NHS organisations reveals a 38-fold variation in expenditure per age-standardised capita in 2009-10^{21,22}.

- It is notable that expenditure is not always aligned with need, or indeed outcome. For example, NHS Cornwall reported average expenditure per capita, despite having amongst the highest levels of incidence.^{23,24}

- Expenditure for eight PCTs more than doubled from 2008-09 to 2009-10, while 12 PCTs reduced their expenditure by more than half over the same time period²⁵.

- There is evidence of inequalities in expenditure on skin cancer, potentially caused by inadequate or inaccurate assessments of local needs.

INCIDENCE AND OUTCOMES FOR SKIN CANCER

Skin cancer is the most common cancer in the UK²⁶. There are two main types: non-melanoma skin cancer and malignant melanoma. Non-melanoma skin cancer is more common, with approximately 99,000 cases diagnosed in the UK in 2008²⁷. It is also less serious than melanoma, or malignant melanoma, which is relatively rare by comparison, making up only 10% of all skin cancers²⁸. The number of people diagnosed with malignant melanoma has more than quadrupled over the last thirty years²⁹. Indeed incidence for both men and women has increased more rapidly than any of the ten most common cancers. This trend is set to continue, with incidence of malignant melanoma in England projected to increase by 88% in men and 66% in women by 2020³⁰. This chapter reviews the latest evidence on how the burden of melanoma falls across the country and population.

The rising incidence of melanoma

There were 9,695 new cases of melanoma in 2008 in England³¹. Melanoma is more common in women than in men; 5,073 cases were diagnosed in women in 2008, and 4,622 cases were diagnosed in men³². Figure 1 illustrates the age and sex distribution of cases between 2006 and 2008 in the UK. It is evident that the burden of melanoma falls heaviest in the over 65s, although more than a quarter (28%) of all cases occur in people aged less than 50 years³³. In 2008, over 900 people diagnosed with malignant melanoma were aged between 15 and 34 years old, making it the second most common cancer in this age group³⁴.

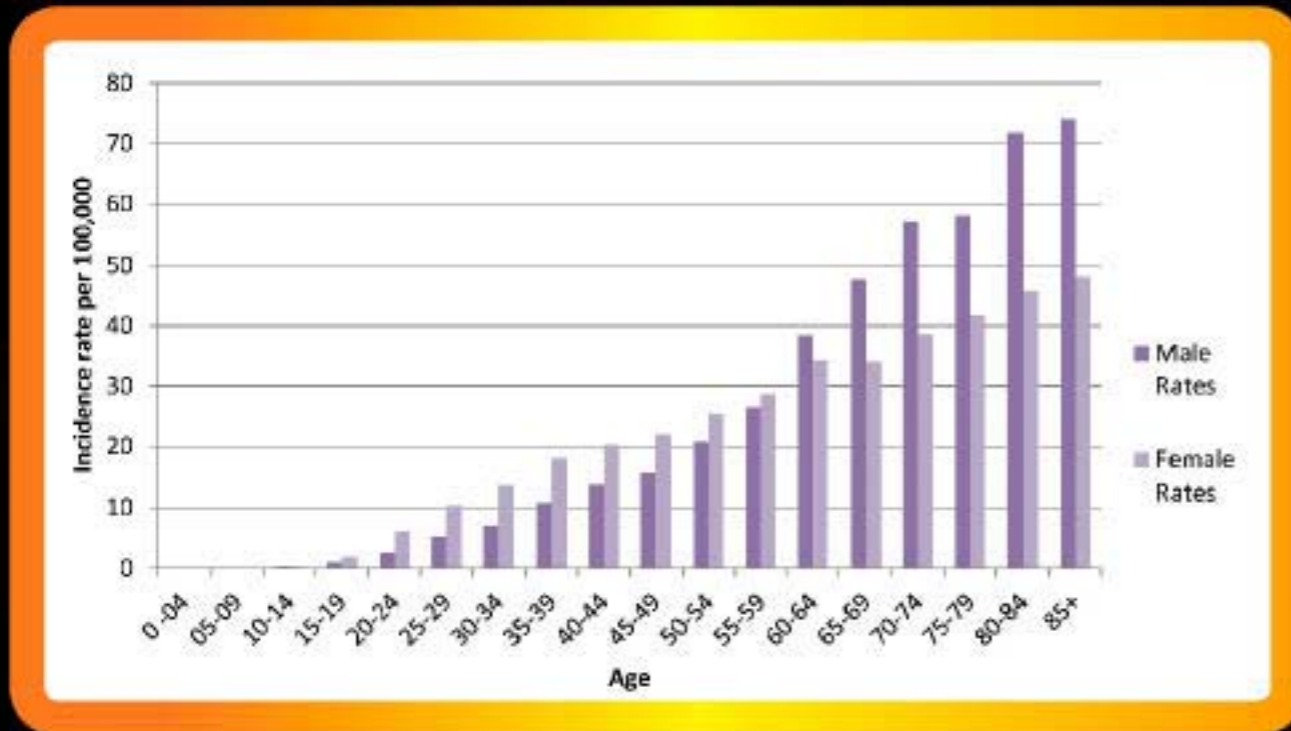


Figure 1: Melanoma incidence rate per 100,000 by age and by sex in the UK (2008)³⁵

Figure 2 demonstrates the geographical distribution of melanoma incidence from 2006 to 2008 in England. The average incidence of melanoma across England during this period was 15.58 cases per 100,000 of the population³⁶. However, the map demonstrates the wide variations in incidence across the country; there is an almost eight fold variation. Plymouth Teaching PCT had the highest incidence rate at 28.7 cases per 100,000 in 2006-08. The lowest incidence rate - 3.69 cases per 100,000 - was in NHS Newham in London³⁷.

Figure 2 clearly illustrates that there are regional patterns in incidence. There is a pocket of high incidence in the South West of the country, part of the newly formed NHS South Strategic Health Authority³⁸. Indeed, over two thirds (70%) of the PCTs with incidence rates in the highest 20% of the country were in NHS South demonstrating the burden of melanoma for this health authority³⁹. 70% of the PCTs with the lowest incidence were in NHS London⁴⁰.

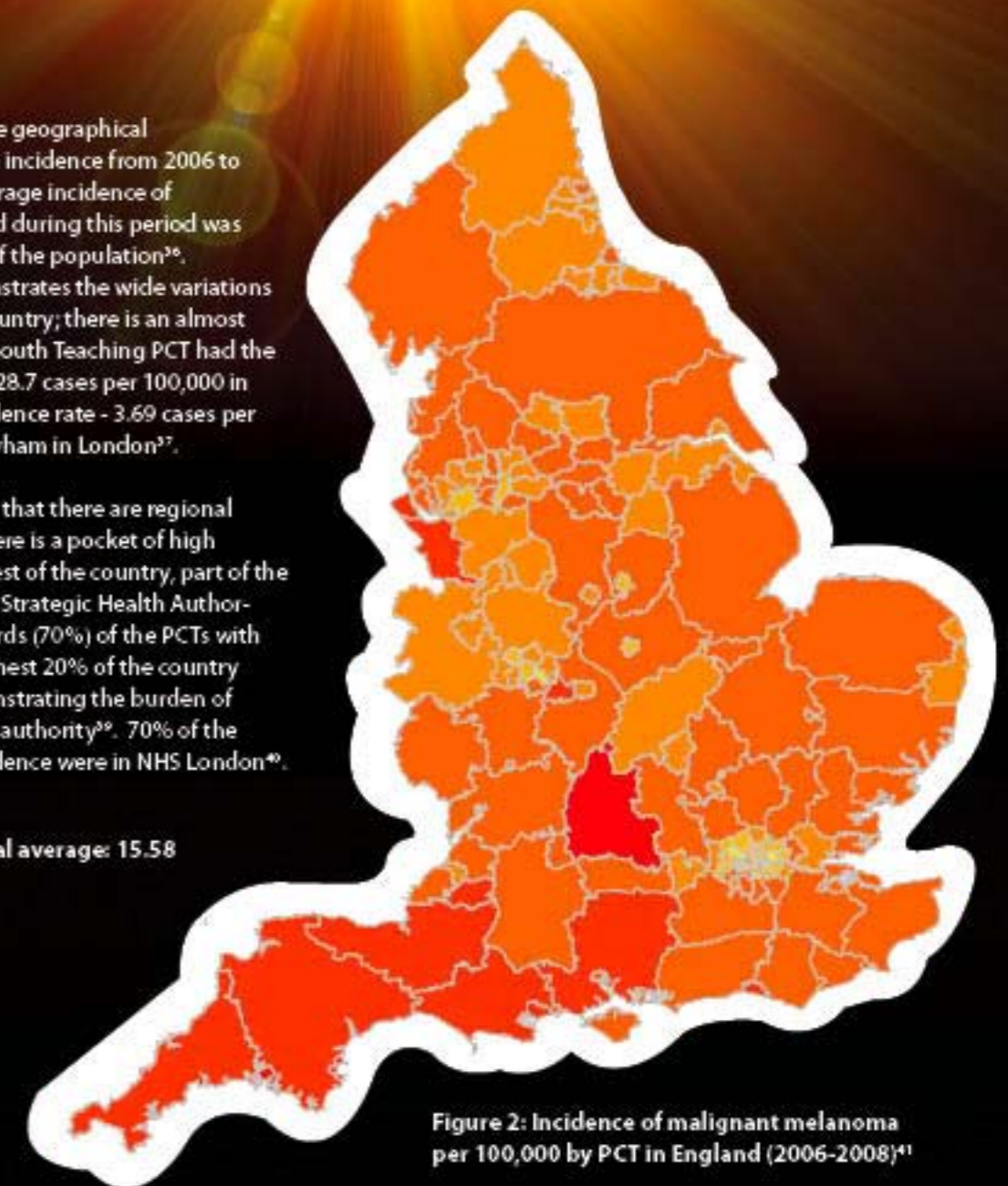


Figure 2: Incidence of malignant melanoma per 100,000 by PCT in England (2006-2008)⁴¹

In addition to age, latitude is another important contributory factor to patterns of melanoma incidence⁴². Figure 3 illustrates the pattern of sunshine hours by PCT between 1960 and 1990 demonstrating the different levels of solar ultraviolet radiation at different latitudes. Comparing this with figure 4 it is evident that there is some correlation between hours of sunshine and incidence rates. Within England, the South West receives the most UV exposure and also has an older population with both contributing to the high incidence of malignant melanoma. However, the increase in the number of people taking overseas holidays and the rise in the use of sunbeds in the last thirty years has disrupted historic patterns and is thought to be an important contributory factor to the sharp rise in incidence rate.

Figure 3: Average sunshine hours by PCT between 1960 and 1990⁴³

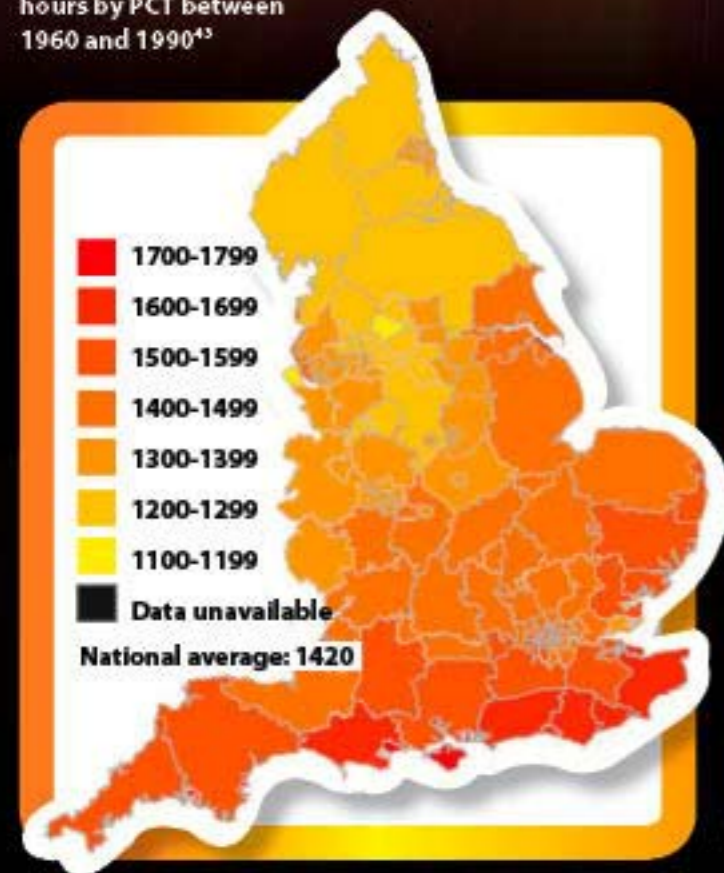
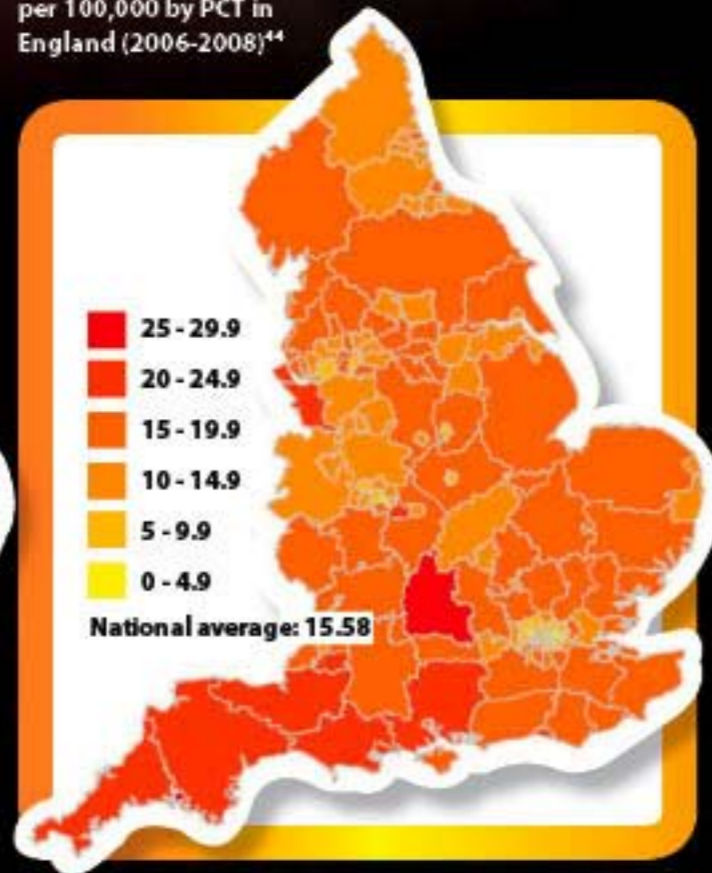


Figure 4: Incidence of malignant melanoma per 100,000 by PCT in England (2006-2008)⁴⁴



Research by the National Cancer Intelligence Network has revealed that Asian and Black populations are at a significantly lower risk of developing melanoma⁴⁵. This is because people with naturally brown or black skin have more melanin pigment in their skin cells which can protect the skin from UV damage⁴⁶. As a result, geographical variations in malignant melanoma incidence can in part be explained by percentage of the white population.

Figure 5 illustrates the percentage of the white population in each PCT. The pattern between ethnicity and incidence is visibly most marked in major cities, such as London and Birmingham. Furthermore, NHS Newham and NHS Heart of Birmingham which both had lowest incidence rates for malignant melanoma in the country in 2006-2008, also had the lowest percentage of white population⁴⁷. Conversely, those PCTs with incidence rates in the top ten highest, had over 90% white population⁴⁸.

Figure 5: Percentage of white population by PCT (2007)⁴⁹

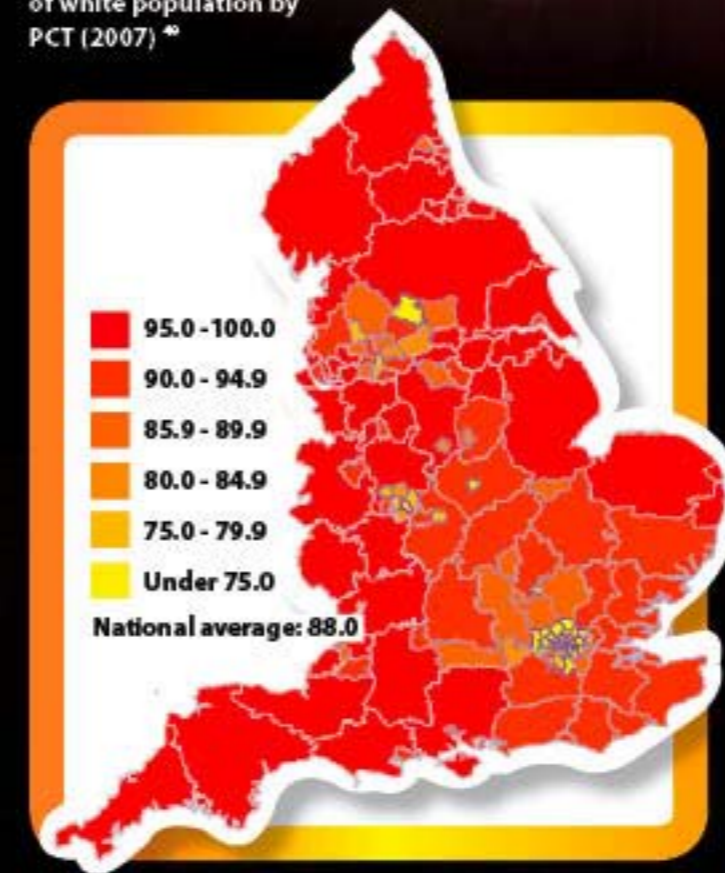
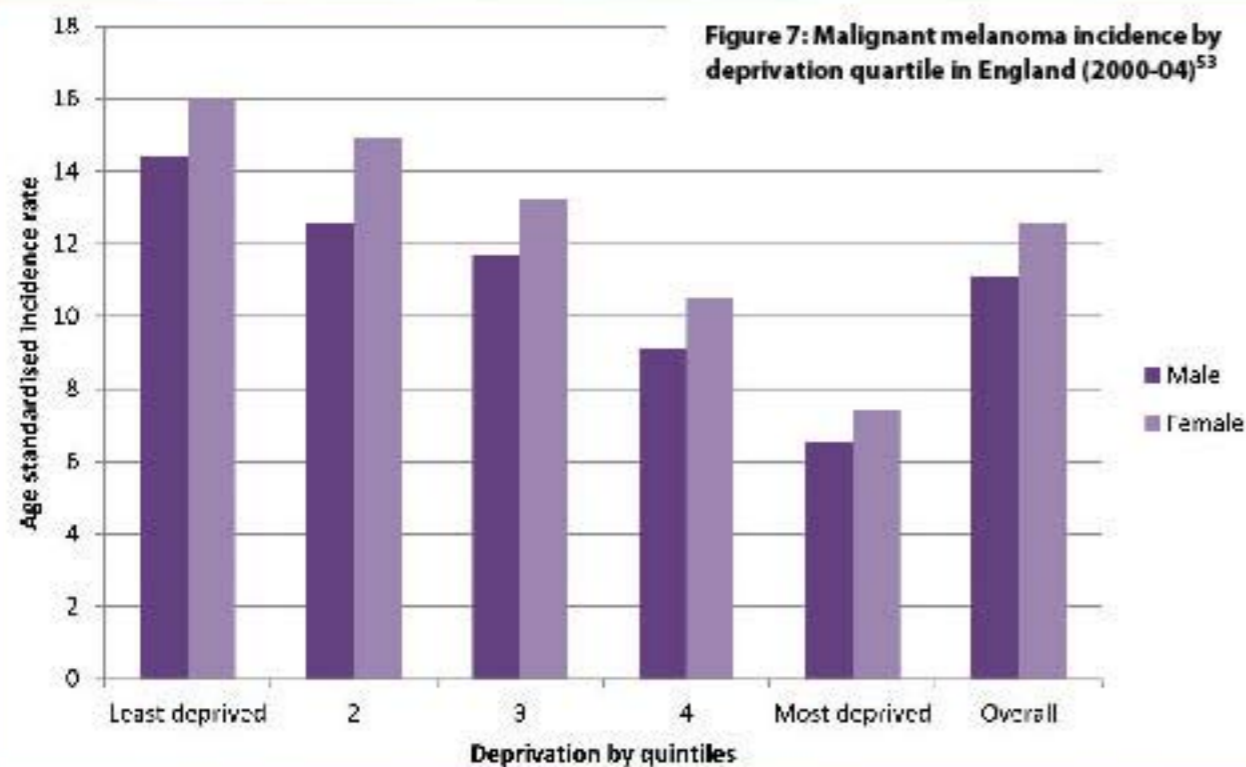


Figure 6: Incidence of melanoma per 100,000 by PCT (2006-08)⁵⁰



Many cancers are associated with deprivation. However, melanoma is associated with affluence. Although the association with affluence has diminished in recent years, it is still notable. Figure 7 below illustrates how, between 2000 and 2004, incidence rates for melanoma were 45% higher in the least deprived quintile of the population compared to the most deprived demonstrating the inverse relationship between socio-economic deprivation and melanoma incidence⁵¹. This difference may be related to access to holidays abroad, where higher intensity sun exposure is likely. This would also explain why the gap in incidence between the least and most deprived groups has narrowed. In 2005, UK residents made a record 66.2 million trips abroad, three times as many as in 1985⁵².



Figures 8 and 9 below illustrates how rates of socioeconomic deprivation by PCT compares to malignant melanoma incidence rates by PCT. Whilst there was no statistically significant trend between these data sets, NHS Newham had one of the highest deprivation scores and the lowest incidence rates whilst the converse is true for NHS Oxfordshire^{54,55}.

However, high levels of incidence are observed in some deprived areas. For example, NHS Blackpool, NHS Liverpool, NHS Hastings and Rother, NHS Knowsley, NHS Salford and NHS Blackburn with Darwen Care Trust, which all have deprivation in the top 20% of the country, also had above average incidence rates for melanoma^{56,57}.

Figure 8: PCT average score of deprivation index (2007)⁵⁸

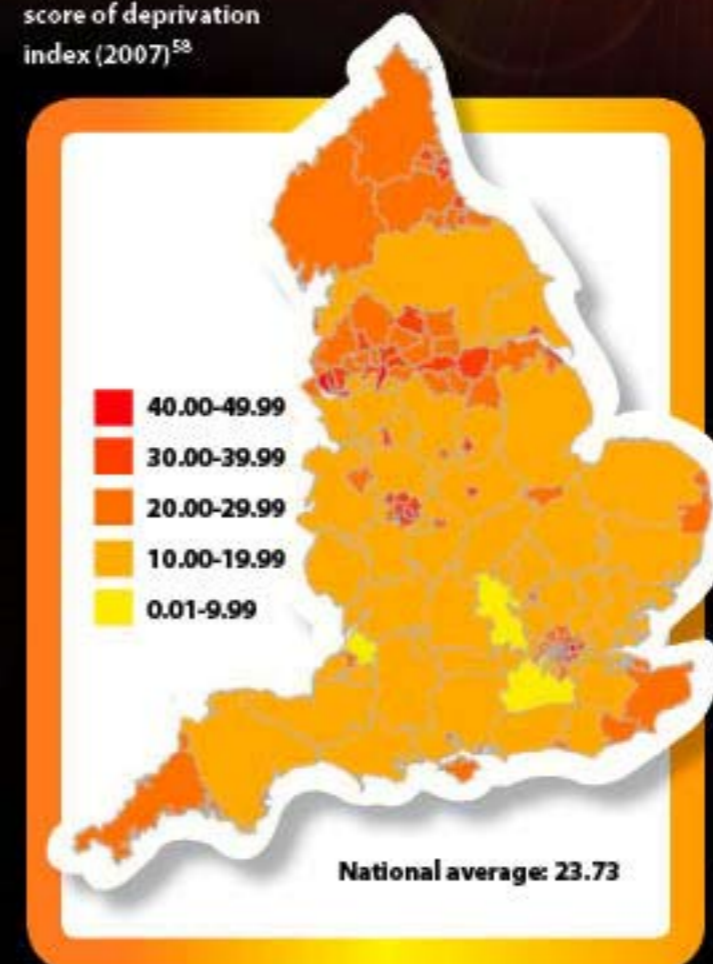
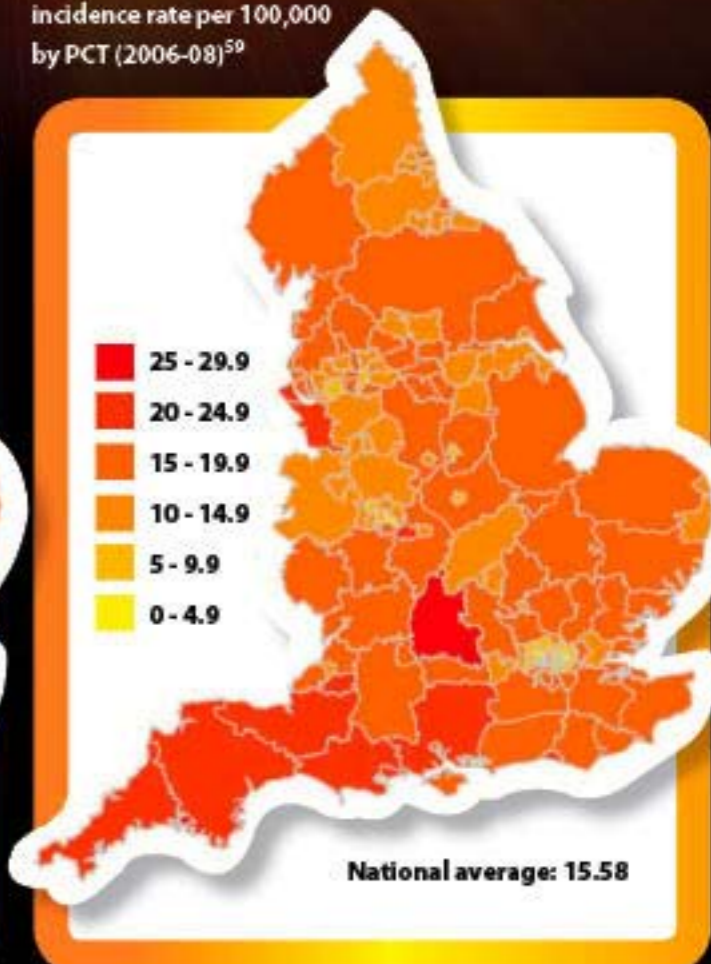


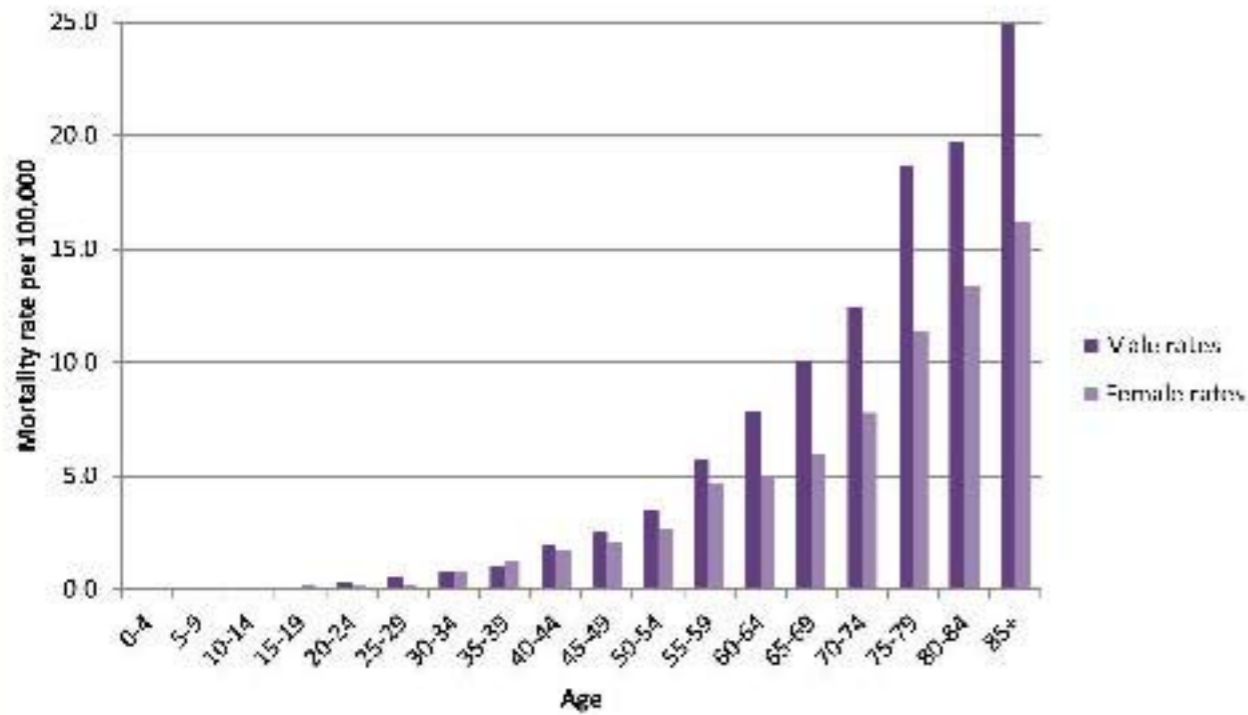
Figure 9: Malignant melanoma incidence rate per 100,000 by PCT (2006-08)⁵⁹



Trends in mortality

There were 1,725 deaths in England from melanoma in 2008⁶⁵. The average mortality rate in England is 2.6 deaths per 100,000⁶⁵. As Figure 10 illustrates, mortality rates rise steadily with age with over half of all deaths from melanoma occurring in patients over 70⁶⁵. Given the age profile of incidence, this is to be expected. However, melanoma kills an unusually high number of young patients for an adult cancer; 110 patients under the age of 40 died from melanoma in 2008⁶⁵. Nationally, in 2008, 40% of deaths were in patients under the age of 65 years old⁶⁴. By comparison, for all tumours, 23% of all cancer deaths were in people under the age of 65s⁶⁵.

Figure 10: Mortality from melanoma by age and sex in the UK (2008)⁶⁶



The geographical distribution of mortality from melanoma is broadly similar to that of incidence as illustrated by Figure 11 with most of the high rates falling in the south of the country. There is also wide variation in mortality with a five-fold variation in the rate of mortality between PCTs⁶⁷.

NHS Plymouth Teaching, which had the highest incidence rate from melanoma in 2008, also had the highest mortality rate with 5.2 deaths per 100,000 of the population⁶⁸. However, mortality in NHS Herefordshire was also very high with 5.09 deaths per 100,000 even though it had an incidence rate at the national average (15.52)⁶⁹. Conversely, NHS Torbay which had one of the highest incidence rates in country, had a mortality rate in the lowest quintile⁷⁰. Conclusions cannot be drawn about the quality of care and treatment by comparing incidence and mortality for one year. However, it does provide an indication of where the burden of melanoma falls in different parts of the country, and how different commissioners will face different challenges in improving outcomes.

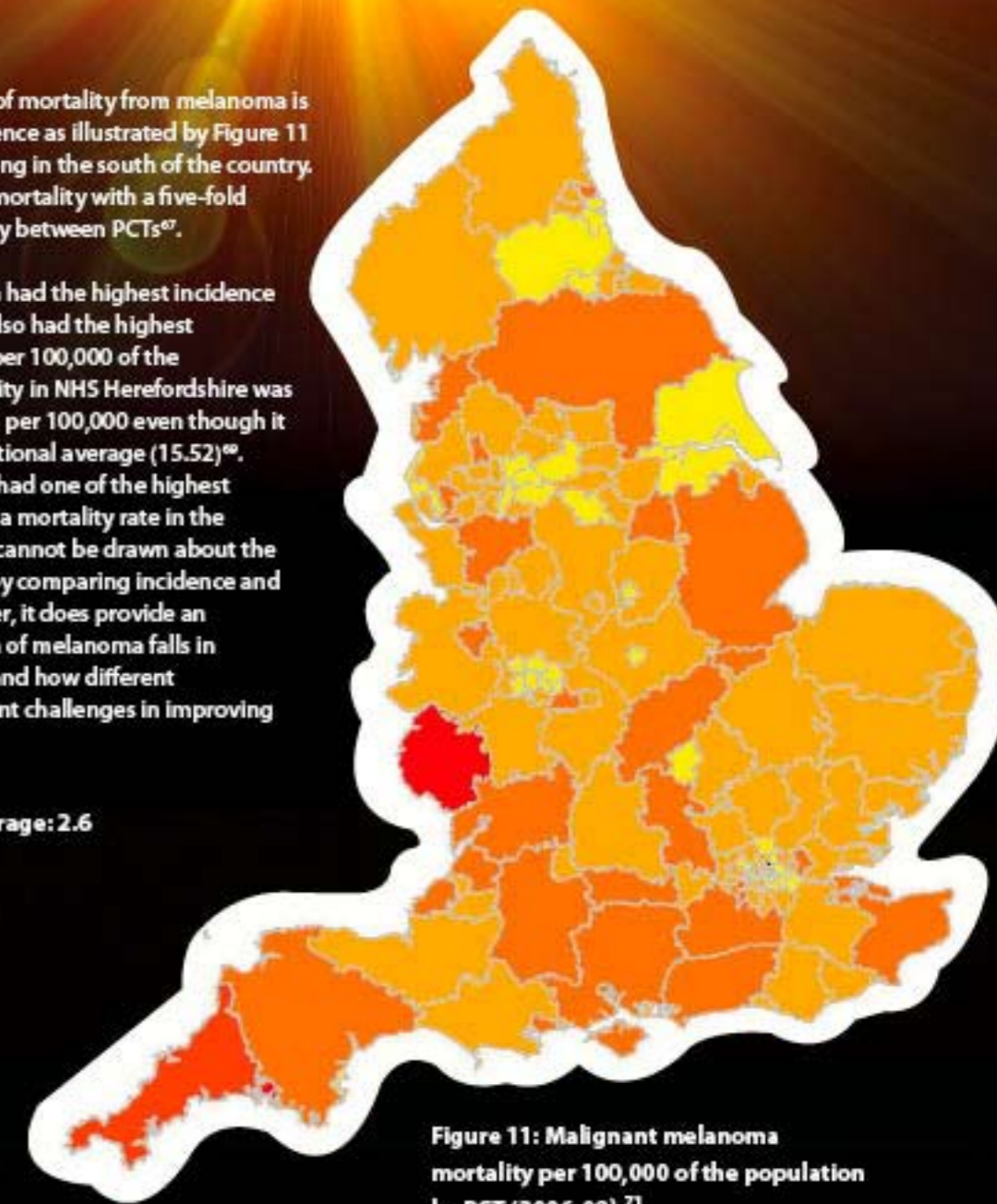
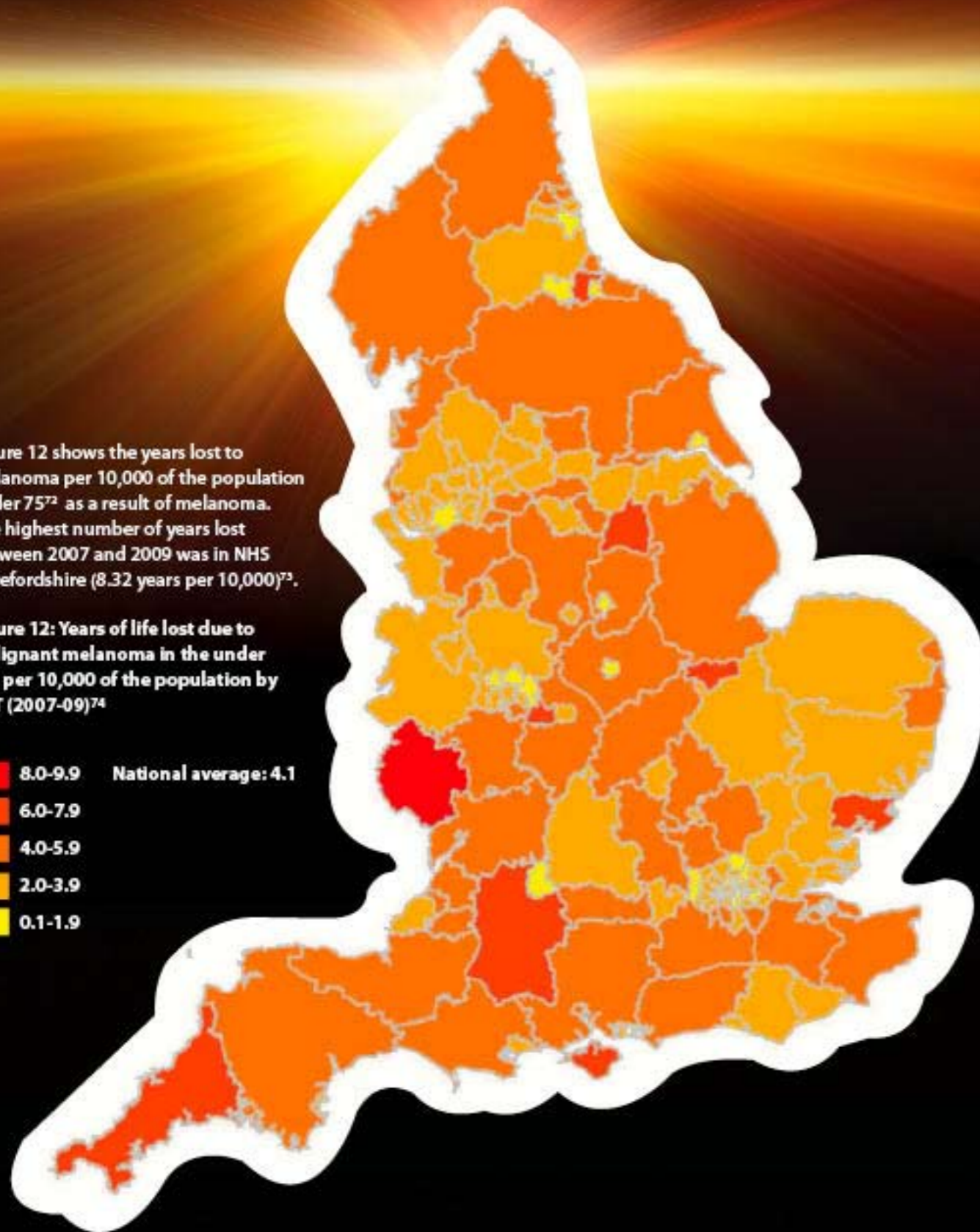


Figure 11: Malignant melanoma mortality per 100,000 of the population by PCT (2006-08)⁷¹

Figure 12 shows the years lost to melanoma per 10,000 of the population under 75⁷³ as a result of melanoma. The highest number of years lost between 2007 and 2009 was in NHS Herefordshire (8.32 years per 10,000)⁷³.

Figure 12: Years of life lost due to malignant melanoma in the under 75s per 10,000 of the population by PCT (2007-09)⁷⁴



Explaining variations in survival

Survival in melanoma is strongly correlated with the depth of invasion at diagnosis, commonly known as the Breslow thickness, and the stage of diagnosis⁷⁵. Encouraging people with changes in their moles to see their GP, and supporting GPs in appropriately referring people at risk of skin cancer, is therefore critical. These issues are explored in the next chapter.

Over the last 30 years, survival rates from melanoma have been gradually improving, with survival rates for women consistently higher than for men. Figure 13 illustrates that five year survival has increased from 46% for men and 65% for women since 1971-1975 to 81% and 90% for men and women respectively in 2001-2006⁸⁰. Melanoma has the highest survival difference between the sexes of any cancer at almost 10% for the latest figures available making gender an important prognosis factor⁷⁷. The reason for poorer survival rates in men can in part be explained by the fact that melanomas are more common in men on less visible parts of the body; in men 41% of melanomas are found on the trunk, particularly the back, whereas for women, 40% of melanomas are found on the leg⁷⁸. This can lead to a delay in patients spotting the signs and symptoms and the tumour being more advanced by the time of the diagnosis. However, the reasons are multiple and complex and there are likely to be a number of other factors such as the propensity to seek early medical advice⁷⁹.

Figure 13: Age standardised five year survival rates by sex from 1971-75 to 2001-06 in England and Wales⁸⁰

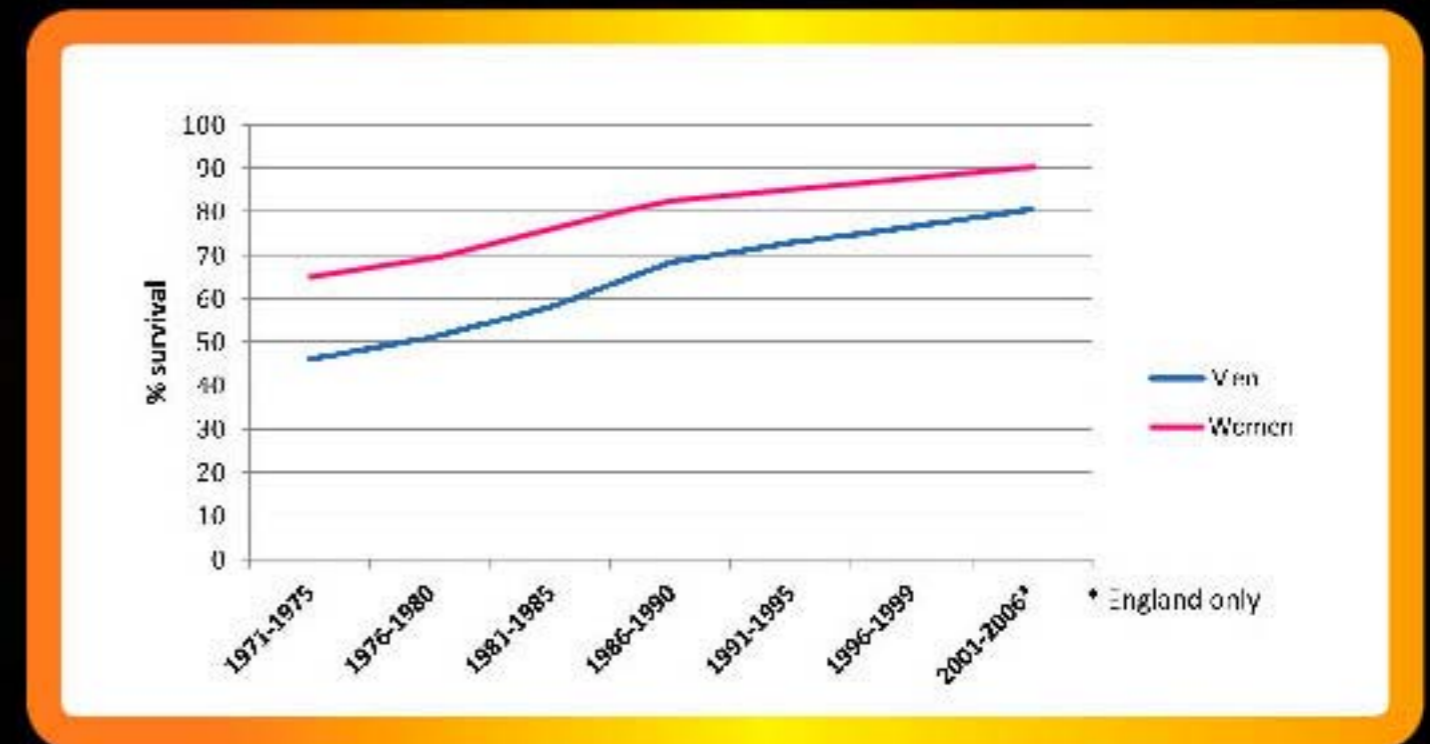


Figure 14 illustrates the regional variation in five year survival between 2000 and 2004, the latest year for which survival data by SHA are available⁶¹. During this period the average survival rate in England was 87.0%. NHS London, which had one of the lowest incidence rates for malignant melanoma, also had the poorest survival rate, with 83.8% of patients alive five years after diagnosis⁶². Survival was lowest in NHS South East Coast (82.9%). NHS South Central had the highest survival rates for this period (90.4%)⁶³. These data were collected before the publication by NICE of *Improving outcomes for people with skin tumours including melanoma*, guidance which set out how the skin MDT should be organised and how it should operate. It is possible that this guidance could have had a marked impact on the quality of services and outcomes of melanoma patients.

Figure 14: Five year survival from melanoma by SHA, 2000-2004⁶⁴

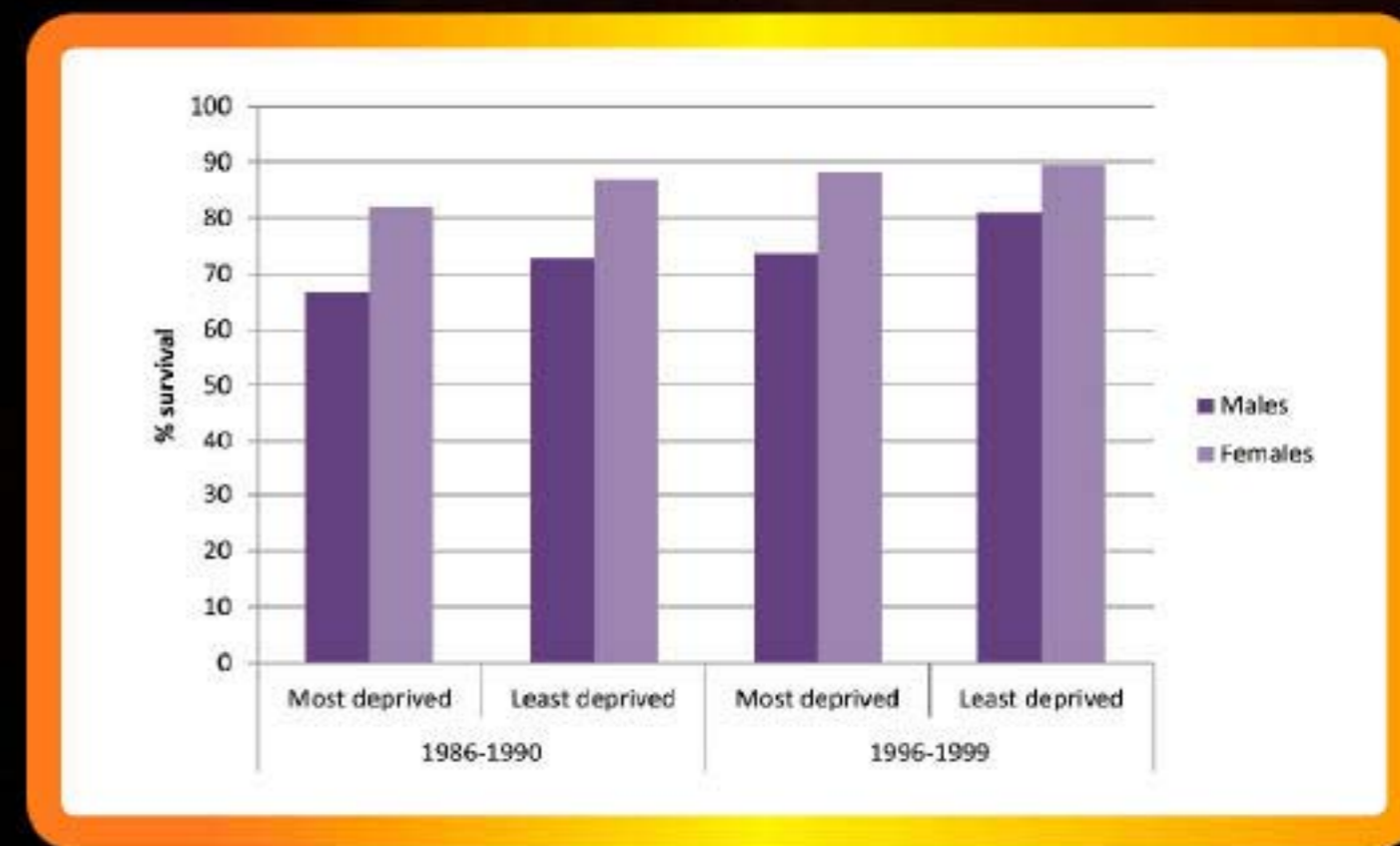


National average: 87.0



Figure 15 illustrates that malignant melanoma survival for adults in England and Wales is lower among patients in more deprived groups, although the gap with the least deprived groups has narrowed since 1986-1990, particularly for women⁶⁵. Research has shown that those from more deprived groups are less likely to be able to recall (ie identify without prompting) or recognise (ie identify from a list of possible symptoms) cancer symptoms than those from less deprived groups⁶⁶. This is likely to contribute to delays in presentation, more advanced disease at diagnosis and subsequently lower survival rates. Other explanations for this gap in survival have been identified by NCIN as differential access to optimal treatments and co-morbidities that impact treatment⁶⁷.

Figure 15: Relative survival in the most and least deprived groups for males and females diagnosed between 1986-90 and 1996-99⁶⁸



PREVENTING AND DIAGNOSING SKIN CANCER EARLIER

Prevention and symptom awareness

The main preventable cause of skin cancer is excess exposure to ultra-violet radiation either from the sun or from sunbed use⁹⁹. Melanoma can start as an existing mole or it can develop in relatively normal-looking skin in any part of the body. The epidemiology of skin cancer, and evidence from Australia suggest that efforts to minimise the burden of melanoma should focus on a reduction of exposure to UV radiation, combined with increased population awareness of the signs and symptoms of cancer to increase the proportion of melanoma patients who are diagnosed early⁹⁹.

Over the last ten years, there have been increasing efforts to educate the public on the risks associated with over-exposure to UV light, and to prevent new incidences of skin cancer, through awareness initiatives such as the Sunsmart campaign and important policy developments such as the Sunbed Regulations Act (2010) which restricts the use of sunbeds by under-18s, and NICE has also published comprehensive guidance on skin cancer prevention⁹¹.

However, more needs to be done to reduce the growing rate of incidence in the UK, through a concerted and co-ordinated effort to drive measurable changes in our behaviour, thereby reducing our exposure to the damaging effects of the sun. As set out in our first report, *Skin Cancer in the UK: The Facts*, Skin Cancer UK is calling for a year-round national public health awareness campaign with a particular focus on school education which teaches school children about sun safety and the dangers of over-exposure to UV⁹². In addition, it should be mandatory for schools to have an enforceable policy on sun safety based on national guidelines for UV exposure⁹³.

The NHS reforms create important new opportunities to improve not just prevention, but also greater symptom awareness. From 2013 a new public health service, Public Health England (PHE), will oversee the improvement and protection of public health through a new public health outcomes framework, and will act as a hub for public health data and intelligence (bringing together the work of the cancer registries, the National Cancer Intelligence Network and public health observatories)⁹⁴.

Subject to the passage of the Health and Social Care Bill 2011, local public health functions will be transferred to local authorities with ring-fenced funding led by local directors of public health. Skin Cancer UK supports a lead role for PHE in national awareness campaigns on sun safety, but calls for local autonomy over how community-based education initiatives are designed and implemented.

Campaigns to improve awareness of the signs and symptoms of skin cancer often draw on the ABCDE checklist⁹⁵ (figure 16) which helps people to tell the difference between a normal mole and a melanoma, and when they should seek help. Given the critical role of GPs in early diagnosis, symptom awareness campaigns should fall under the responsibility of the NHS Commissioning Board and clinical commissioning groups.

Figure 16: ABCDE checklist⁹⁶



More fundamentally, skin cancer prevention and education needs to be embedded within communities, as a normal and routine feature of personal, family and social life. Success on prevention will be an important measure of the success of the new public health institutions and structures, and the ability of the system to drive a more integrated approach to planning and delivering services.

Local health and wellbeing boards will have a critical role to play in assessing the needs of the local community in relation to skin cancer risk through the Joint Strategic Needs Assessment, and developing an integrated plan that will drive joint commissioning solutions across the NHS and local authorities. This means pooling resources to ensure that initiatives reach into schools, workplaces, and public spaces, and link back into a robust and effective primary care response.

Recommendation 1: PHE should develop a strategy to ensure the delivery of consistent public health messaging on sun safety and the dangers of over-exposure to UV at a national and local level

Recommendation 2: Interventions should be targeted at high risk groups including deprived communities and men to increase awareness of the signs and symptoms of melanoma and encourage them to present earlier to their GP

Early diagnosis

The stage of a melanoma describes how deeply it has grown into the skin, and whether it has spread⁹⁷. Doctors use different scales to determine the stages of melanoma. TNM stands for Tumour, Node, Metastasis:

- T describes the size and nature of the tumour
- N tells you whether or not the cancer has spread to the lymph nodes
- M tells you whether or not it has spread to the rest of the body⁹⁸.

Although registration of skin cancer incidence is comprehensive, recording of stage is less so, with NICE estimating that nearly a quarter of cases do not have staging recorded⁹⁹.

Figure 17: Percentage survival for more than 5 and 10 years at different stages of melanoma diagnosis¹⁰⁰

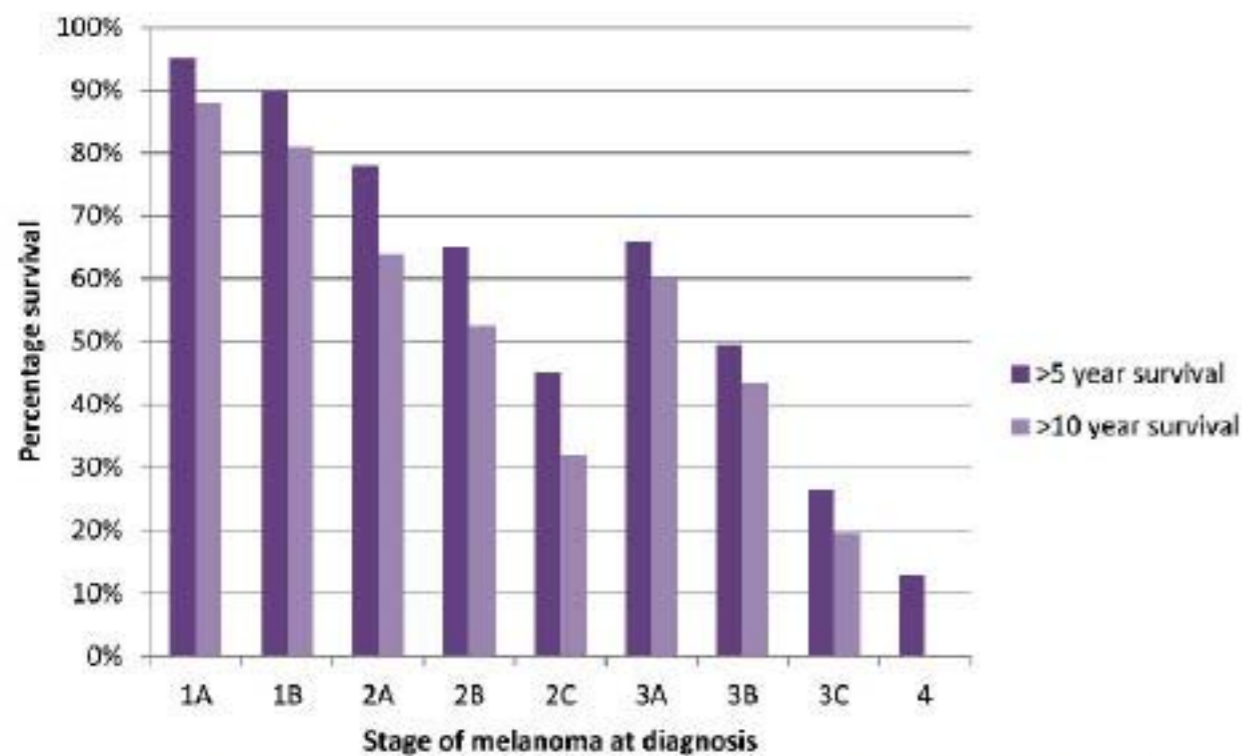
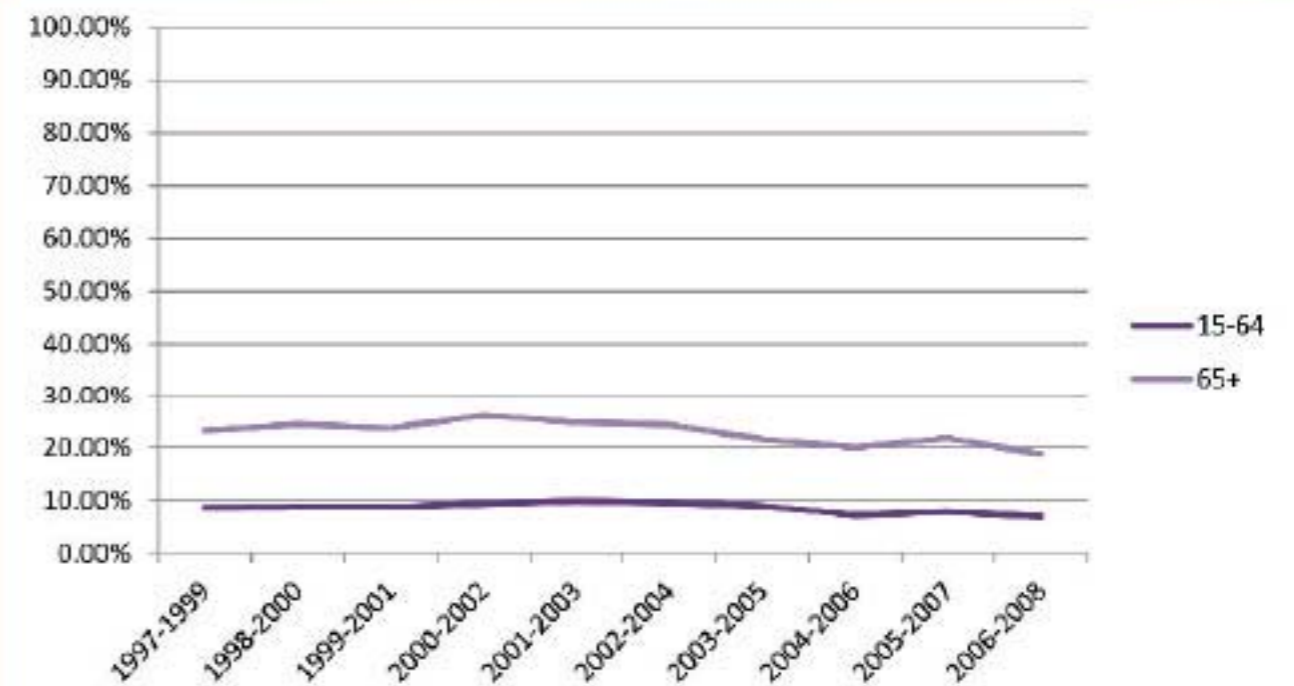


Figure 17 shows that efforts to diagnose cancer early are likely to have the greatest overall impact on survival. However, a fifth of patients are diagnosed with advanced disease¹⁰¹ when melanomas have spread to nearby lymph nodes (stage 3) or elsewhere in the body (stage 4) such as the lungs, liver or brain or to distant lymph nodes or areas of the skin. Outlook for advanced melanoma is much poorer, and for these patients it is important to focus our attention on improving their outcomes and experiences – for example, by extending their survival and improving their quality of life.

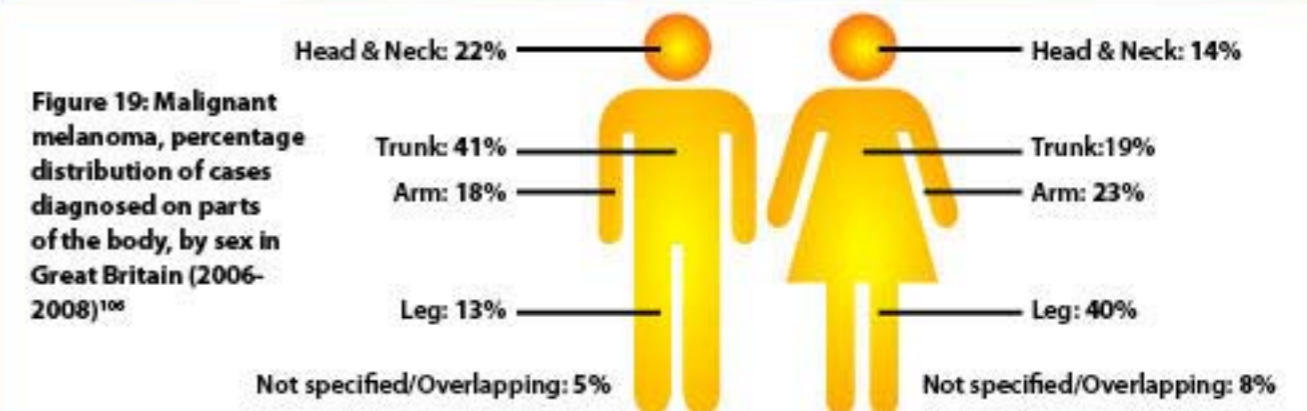
Significantly, more people aged 65 and over are diagnosed with malignant melanoma at a late stage than those under 65 (see Figure 18). According to data from the Eastern Cancer Registration and Information Centre (ECRIC), between 2006-2008 seven per cent of 15-64 year olds diagnosed with malignant melanoma were at a late stage compared with around 20 per cent of those aged over 65¹⁰².

Figure 18: Percentage of people diagnosed within each age-group with late stage malignant melanoma, three year rolling average (1997-2008)¹⁰³



Compared to other rare cancers, the early diagnosis of melanoma is relatively high. Around 80% of melanomas are found at an early stage when the chance of treating the disease effectively is very high¹⁰⁴.

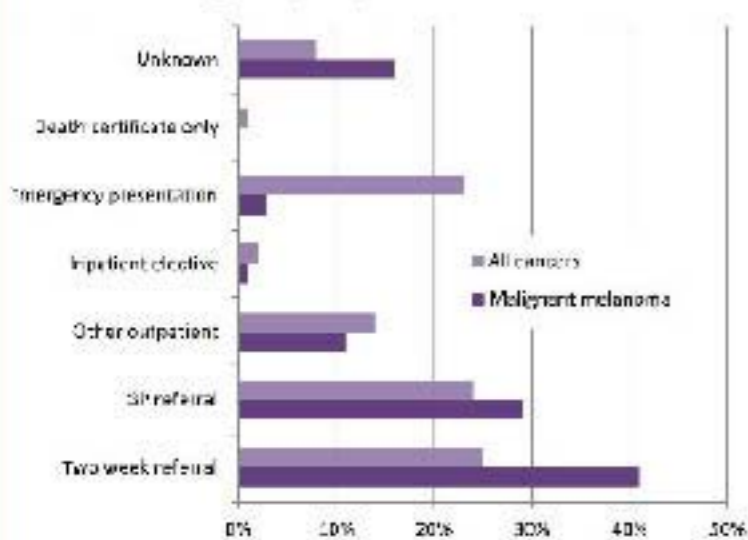
Figure 19 below illustrates the percentage distribution of cases in each part of body for men and women. For women, it is most commonly found on the leg, whereas for men, it is more commonly found on the trunk¹⁰⁵.



Visiting the GP

Awareness is only an effective intervention if patients act upon their concerns. Some patients feel scared or embarrassed or have a negative attitude towards cancer treatment, which means that they delay seeking help, even when they might have an understanding of their symptoms. In a study conducted by the Rarer Cancers Foundation, four in ten respondents with a rarer cancer waited for more than three months between noticing symptoms and seeking help¹⁰⁷. More should be done to reassure patients about the importance of seeking help early.

Figure 20: Routes to diagnosis of malignant melanoma in England (2007)¹⁰⁹



Diagnosis following an emergency presentation was lower for skin cancer (3%) than for any other cancer¹¹⁰. This is particularly important given that one year survival for skin cancer patients diagnosed following an emergency presentation is 61% compared to 97% for diagnosis through all other routes¹¹¹.

Although overall melanoma patients are well supported through the urgent two week referral route, there is variation across the country in how quickly patients are referred to hospital after seeing their GP. Data from the National Cancer Patient Experience Survey in 2010 provide a more detailed picture of how quickly and effectively patients are managed at the beginning of the pathway around the country¹¹². Not all trusts provided responses from skin cancer patients, and those with fewer than 20 responses have not been included, as the results would not be statistically significant.

GP referral

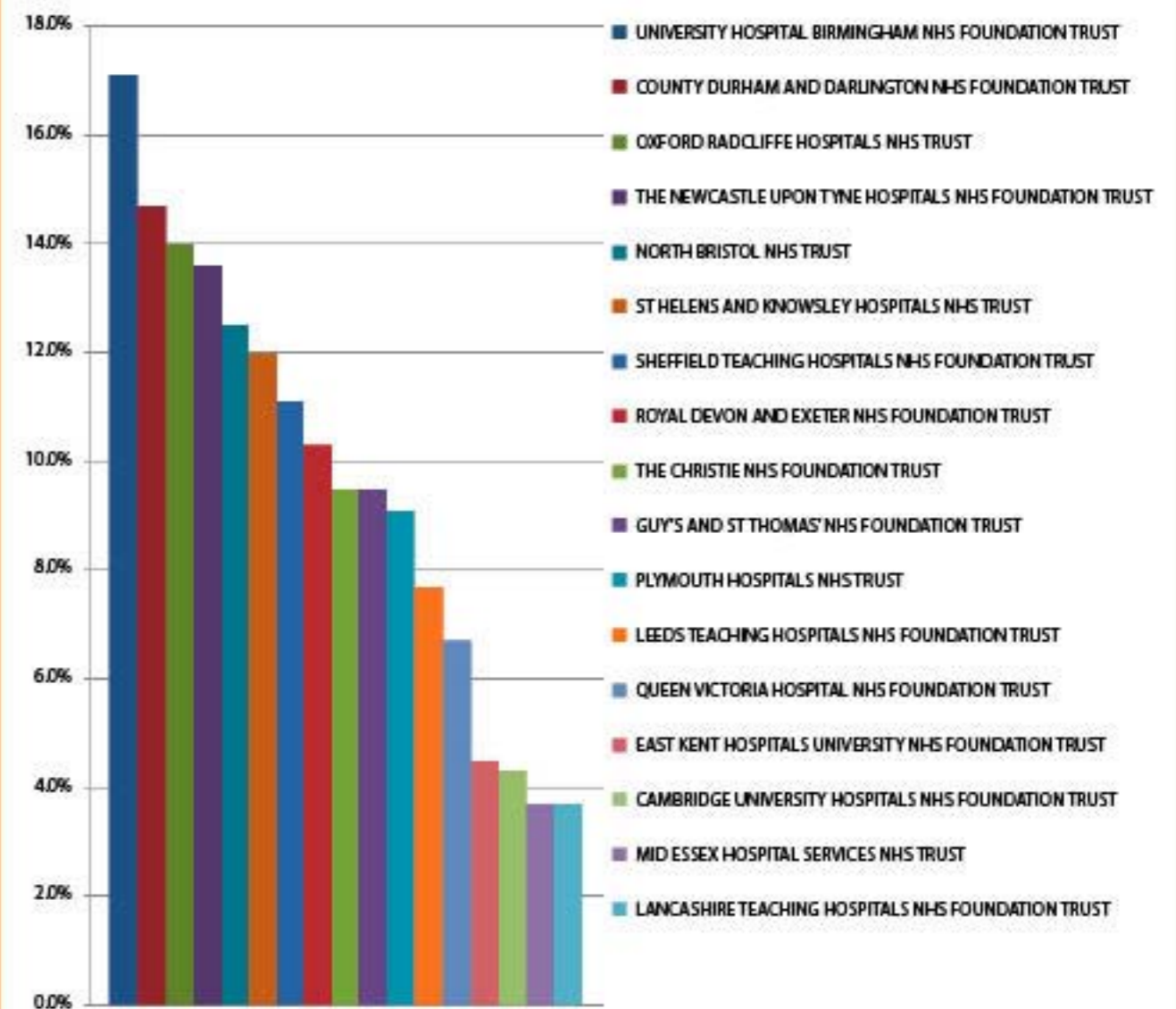
There are a number of other steps that services should take to drive earlier diagnosis for patients who have entered the system:

- Improving access to diagnostic testing within primary care to enable GPs to identify which patients should be referred rapidly through the urgent referral pathway
- Ensuring that patients with suspected malignant melanoma are referred urgently to a local hospital skin cancer or specialist skin cancer MDT (LSMDT or SSMDT)

Research published by the NCIN shows that a higher proportion of malignant melanoma patients were diagnosed through the Two Week Wait urgent referral route than the all cancer average, as set out in Figure 20¹⁰⁹.

Figure 21 shows the proportion of patients who saw a GP more than twice before referral to hospital. All patients being treated at Norfolk and Norwich University Hospitals NHS Foundation Trust, and Salisbury NHS Foundation Trust reported seeing their GP just once or twice before being referred to the hospital, while 17% of patients at the University Hospital Birmingham NHS Foundation Trust had seen their GPs more than twice before being referred¹¹³. Overall, 9% of patients said that they saw their GP more than twice¹¹⁴ – this suggests that some opportunities to refer appropriately from primary care and diagnose cancer more quickly are being missed. Data have been analysed by secondary care provider. It is, however, important to note that missed opportunities to identify signs and symptoms and refer accordingly will not be the fault of secondary care providers.

Figure 21: Percentage of patients who saw GP more than twice before referral to hospital¹¹⁵

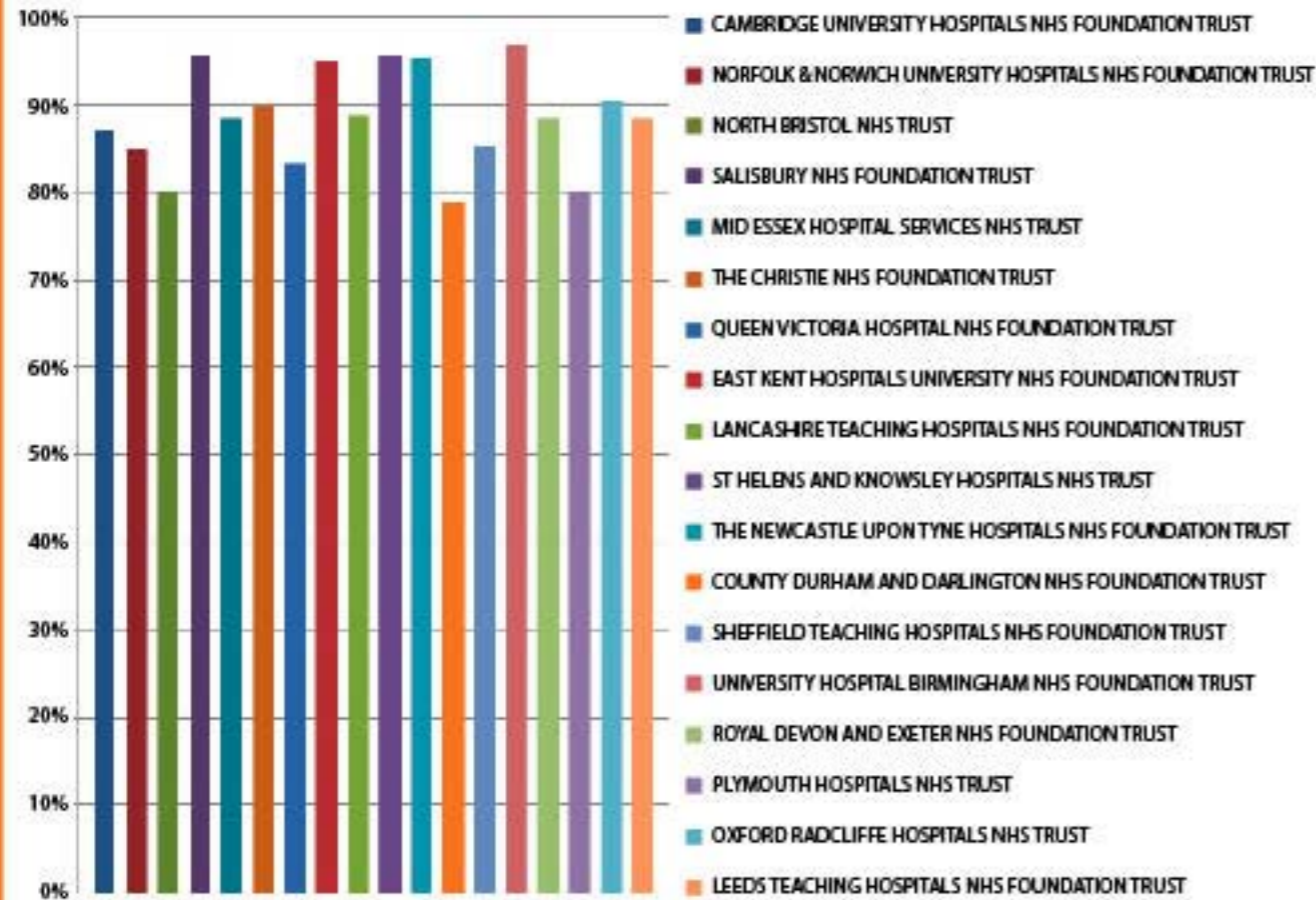


Hospital waiting times

Waiting times for a first appointment with a hospital doctor also vary significantly around the country as shown in figure 22.

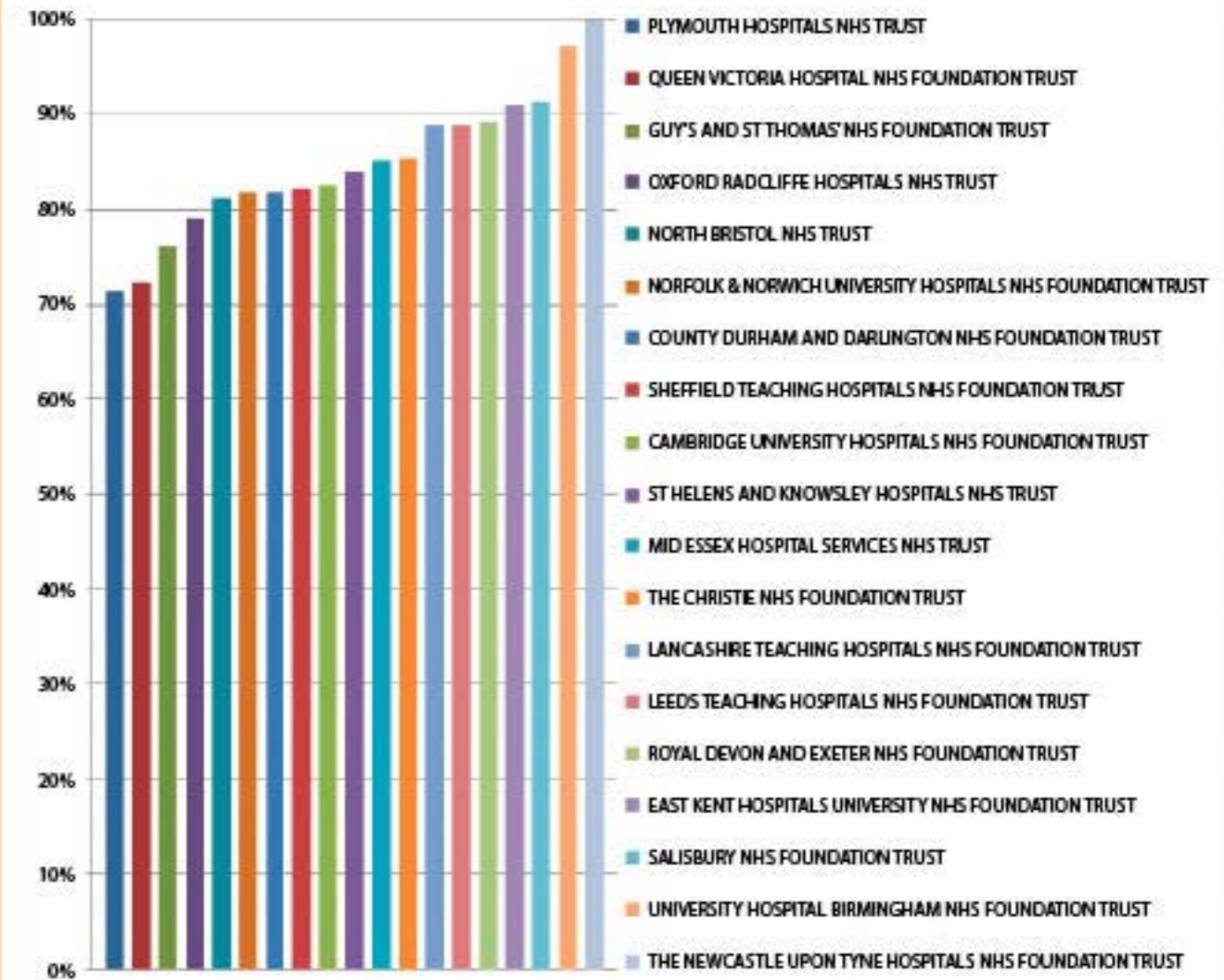
While the majority of patients do see a hospital doctor within four weeks, in three trusts with responses from skin cancer patients, County Durham and Darlington NHS Foundation Trust, North Bristol NHS Trust and Plymouth Hospital NHS Trust, one in five patients had waited more than a month to attend an appointment¹¹⁶. The Department of Health has set waiting time standards of two weeks from urgent GP referral for suspected cancer to first hospital assessment¹¹⁷. Significantly, 61% of patients who said they had seen their GP said they waited two weeks or less before their first appointment with a hospital doctor. While it is not possible to disaggregate patients who were referred through the two-week referral pathway, it will be important to continue to build on progress against this target both to improve the experiences of individuals entering the system, and expedite the patient journey.

Figure 22: Percentage of patients who waited no more than four weeks for a first appointment with a hospital doctor¹¹⁸



Waiting to see a specialist for a suspected cancer can damage a patient's experience of care. It can be a stressful and unsettling period for patients. It can also allow their cancer to spread. It is heartening that most skin cancer patients felt they were seen as soon as necessary (as shown in figure 23), although there are pockets of concern. For example, in four providers over a fifth of patients felt they were not seen as quickly as they should be¹¹⁹.

Figure 23: Percentage of patients who felt that they were seen as soon as necessary by a hospital doctor¹²⁰



The IOSC also recommends that 95% of skin cancer patients should begin treatment within two months of an urgent referral¹²¹. Awareness raising activity will increase the number of patients coming into the system. It will be important to ensure that there is sufficient capacity and the right skills within secondary care to manage the additional demand and ensure that patients requiring urgent referral are seen by a specialist as soon as possible.

Recommendation 3: Initiatives to raise awareness of the signs and symptoms of melanoma must be properly evaluated by the Cabinet Office's Behavioural Insight Team to better understand the interventions which drive behaviour change, and good practice examples should be disseminated to local services via the NAEDI

Recommendation 4: The Department of Health and Public Health England should develop joint commissioning indicators for skin cancer

Recommendation 5: Commissioners should ensure that providers adhere to agreed standards on cancer waiting times for patients with malignant melanoma, including the two-week urgent referral pathway, and two months wait from urgent referral to treatment

IMPROVING OUTCOMES FOR CANCER PATIENTS: BETTER TREATMENT

The IOSC highlights the critical role of appropriate treatment, delivered to a high standard, in improving outcomes for cancer patients¹²². For skin cancer, treatment can take a number of forms, including surgery, radiotherapy and drug treatment.

Delivering high quality treatment requires a number of factors:

- Appropriate access to multi-disciplinary expertise
- Adequate capacity to deliver treatment
- Funding for the most appropriate interventions

Given the expected increase in the numbers of patients requiring treatment, it will be vital that commissioners plan ahead to ensure that these factors are in place.

Surgery

Most early stage melanomas can be treated through a wide local excision which may involve removal of the lymph nodes close to the tumour site¹²³. The quality of surgery has improved with advances in surgical techniques, resulting in less invasive procedures and better outcomes¹²⁴.

A briefing produced by the National Cancer Intelligence Network (NCIN) shows variations in the proportion of patients receiving major surgical resections for thirteen different cancer sites¹²⁵. The study shows a large reduction with age in the percentage of patients receiving a major resection, even for patients over 50¹²⁶. For patients aged 80 or over, less than 2% had a record of a major resection for six of the thirteen cancer sites analysed¹²⁷. Skin tumours were not included in the study, but given that the burden of melanoma falls heaviest in the over 65s¹²⁸, it will be important for services to collect data on active treatment rates for melanoma in order to evaluate the extent to which patients are able to access surgical interventions that can improve their outcomes.

Once a patient has undergone surgery, it is important to put in place appropriate after care and ongoing support. Surgery for skin cancer can, by its very nature, be disfiguring. All patients should therefore have access to emotional and psychological interventions, as well as support and advice on coping skills, camouflaging advice, occupational therapy, as well as any necessary reconstructive surgery¹²⁹.

Radiotherapy

Radiotherapy has a more limited role in the management of patients with malignant melanoma, but it is sometimes given after an operation to remove the lymph nodes, to reduce the risk of melanoma coming back in that area¹³⁰.

Drug treatment

Even with improved prevention and awareness, patients will continue to develop metastatic melanoma and it is important that their needs are met. A very small minority of people with advanced disease can still have their tumour removed through surgery. Chemotherapy is often used for patients with metastatic melanoma as it can slow down the progression of the disease.

Treatment options for patients with advanced or metastatic malignant melanoma have historically been limited, and until recently, there have been no major breakthroughs in the treatment of malignant melanoma in the last 30 years. Patients are usually managed by a specialist oncologist and treatment normally involves the administration of carboplatin-based chemotherapy or dacarbazine¹³¹. Only an estimated 10-20% of patients respond to this treatment.

However, new treatments for metastatic melanoma will increase the choice and opportunities for patients with metastatic disease. These treatments work in different ways, increasing a patient's likelihood of responding to treatment; either by targeting a particular gene mutation present in some melanoma patients or, by activating the body's immune system to fight melanoma. This means that skin cancer patients will be able to benefit from increased survival and improved quality of life, the kind of advances that have helped other patients with other cancers.

However there are several challenges in ensuring eligible patients are able to access new melanoma treatments. They come at a high unit cost and they can require additional capacity in diagnostic testing, pathology and acute care. It is therefore vital that NHS services plan for the introduction of these treatments, making sure that they have appropriate policies, funding and capacity in place to make them available to patients in a timely fashion.

For example, advances in the development of targeted treatments which are tailored to the particular biological characteristics of the cancer, can help smaller cohorts of patients within a particular tumour grouping. In order for patients to get the most out of these developments, it is critical that they are in a position to access high quality testing at the right stage of the pathway, so that clinicians can identify the most effective treatment for them. In skin cancer this would mean a patient undergoing a test to see if their melanoma cells have a BRAF mutation¹³². Tests must be performed to a high specificity at the right time, to ensure they are accurate and that patients do not miss out on the treatment that could benefit them the most.

It is also important that new treatments are evaluated using the right evidence and in such a way which reflects both the difficulties in generating evidence in small groups of poor prognosis patients, as well as the value that society places on supporting people near the end of their life. NICE is able to exercise additional flexibility for treatments used near the end-of-life in small populations, reflecting these challenges¹³³. It is critical that NICE uses this flexibility as it evaluates new treatments for skin cancer, in order to redress the legacy of unmet need in this clinical area.

The Cancer Drugs Fund

The Cancer Drugs Fund (CDF) was established in October 2010 to ensure that patients can access cancer treatments that are recommended by their clinician, but which are not routinely available on the NHS. It is intended to provide an interim solution to problems relating to access to cancer drugs (such as variations and delays in access to treatments through the exceptional cases process) ahead of the introduction of a new medicines pricing system in 2014¹³⁸. The CDF also creates a vital mechanism through which to pay for testing which can determine which treatments are appropriate for individual patients.

To date, over 5,000 patients have benefitted from the CDF across England¹³⁹. The lack of newly licensed treatments means that melanoma patients have gained less from the CDF than other cancer patients so far. But a new option for treating metastatic melanoma is now available that could be accessed through the CDF.

What treatments are included under the CDF?¹³⁶

The CDF is designed to enable access to cancer drugs, including:

- Those appraised by NICE and not recommended on the basis of cost-effectiveness, or where there is restricted access
- Those on which NICE has not or is yet to issue appraisal guidance
- Near-label treatment (drugs licensed for a common form of cancer but that could benefit a patient with a rarer form of biologically similar cancer)
- Radiopharmaceuticals
- Molecular diagnostic testing to aid targeted use of drugs for patients who are most likely to benefit

The CDF is administered on a regional basis, through each strategic health authority. If a clinician feels that a particular treatment would be of benefit to their patient, that is not routinely available through the NHS, he or she can apply to the CDF to fund the treatment.

Each SHA has developed a list of treatments that will automatically be approved if a patient meets the appropriate clinical criteria. These treatments should be accessed quickly through the CDF as the majority of patients will have a small window when they are eligible for treatment. Guidance published by the Department of Health states that priority lists should be kept under regular review and should not be viewed as exclusive¹³⁷. Applications for treatments that are not on this list should be considered on a case-by-case basis.

Despite the publication of best practice guidance, the utilisation and administration of the CDF varies around the country. We have used the latest available data published by the Rarer Cancers Foundation to analyse the operation of the CDF in different parts of England.

Figure 24: CDF approval rate by SHA (October 2010 - June 2011)¹³⁸

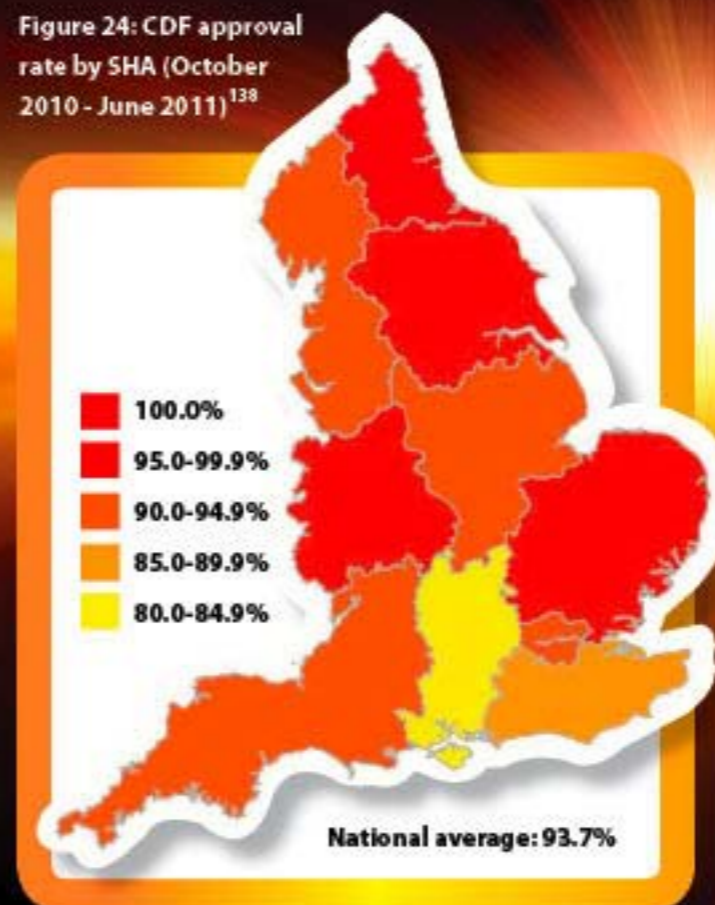
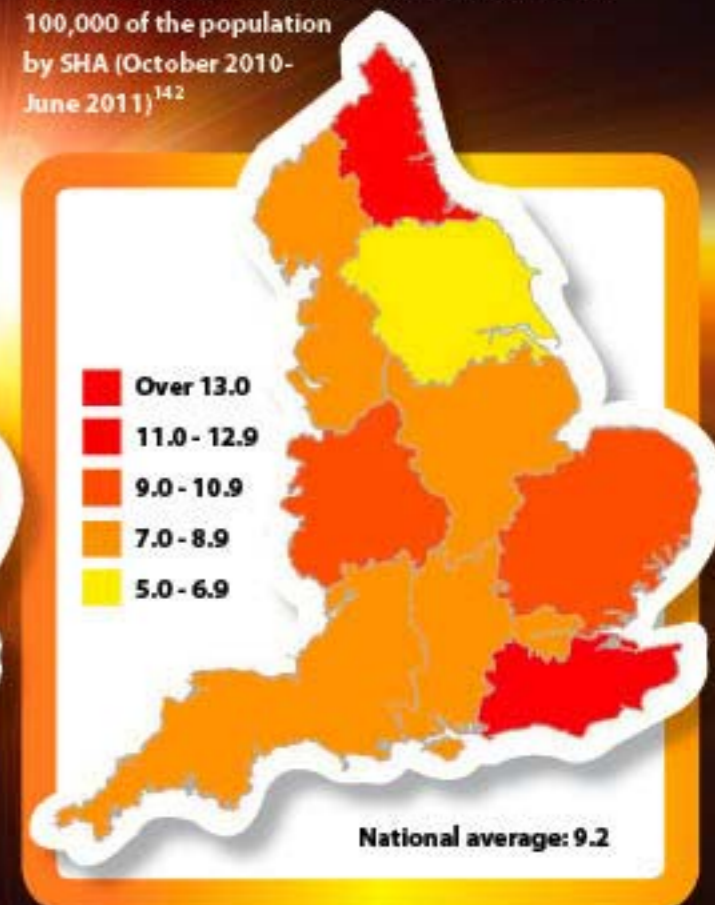


Figure 24 shows that between October 2010 and June 2011, SHAs in the south of England approved a lower proportion of applications. For example, NHS South Central approved approximately 76% of applications whereas NHS North East approved every application it received¹³⁹. Some of this variation is likely to be due to the different processes being used in each SHA¹⁴⁰.

When considering the approval rates of each SHA, it is also important to take into account the rate of application which shows the degree to which clinicians are choosing to access the Fund on behalf of their patients (see figure 25). For example, NHS Yorkshire and the Humber approved 98% of applications but had the lowest rate of applications at 5 applications per 100,000 of the population¹⁴¹.

There is also significant variation in application rates. Between October 2010 and June 2011, NHS South East Coast has received around twice as many applications as NHS North East. This issue requires further examination, but could in part be due to the differences in the way that SHAs assimilate funding requests and make decisions about which

Figure 25: Cancer Drugs Fund application rate per 100,000 of the population by SHA (October 2010 - June 2011)¹⁴²



drugs they will fund. Population-based approaches used by different SHAs were deemed to improve transparency, equity and speed of decision making (decisions were sometimes made within days of a completed application being submitted)¹⁴⁰. It will be important to ensure that SHAs create the right environment which encourages clinicians to make applications based on the needs of their patients.

Evidence from the Rarer Cancers Foundation suggests that there are sufficient funds to make all treatments that clinicians wish to prescribe available to their patients. In the first six months of the Fund, just over half of the £50 million allocation was used although the demand on the Fund is increasing over time¹⁴⁴.

SHAs should therefore pay attention to application and approval rates in their area and take steps to ensure that patients are able to access the same range of drugs as patients living elsewhere, and that local clinical panels respond effectively to the growing needs of melanoma patients with advanced disease in their area.

Length of stay

Following treatment it is important for patients that they are well-supported in their recovery, and that they are able to leave hospital as soon as appropriate. There are usually variations in patient discharge even among patients admitted with similar conditions both within and among hospitals. These can be explained in part due to the way that different processes are managed such as ward rounds and in patient tests¹⁴⁵, as well as the need to carefully manage complex individual cases - but other factors can include a patient's preparedness for treatment and in the instance of cancer, the extent to which more invasive surgery is required.

Aside from improving the patient experience, reducing the length of stay releases capacity in the system but requires effective planning of the whole process of care, as well as active discharge planning.

Figure 26 shows that patients admitted as an emergency have a longer length of stay in hospital than those who are admitted as elective patients¹⁴⁶. Some of the data is affected by a small number of patients in particular areas, so the major outliers have been removed. It may be possible to explain these trends in a number of ways. Firstly, emergency presentations are more likely to be for melanoma that has spread, and may require more invasive surgery, for example to remove nearby lymph nodes - this in turn may require longer periods of recovery in hospital.

Secondly, for patients with skin cancer, delivering planned rather than emergency surgery, can increase a patient's preparedness for treatment, and reduce the overall trauma for the patient, supporting faster recovery and discharge times.

Figure 26: Average length of stay for elective and emergency patients admitted with a primary diagnosis of skin cancer¹⁴⁷

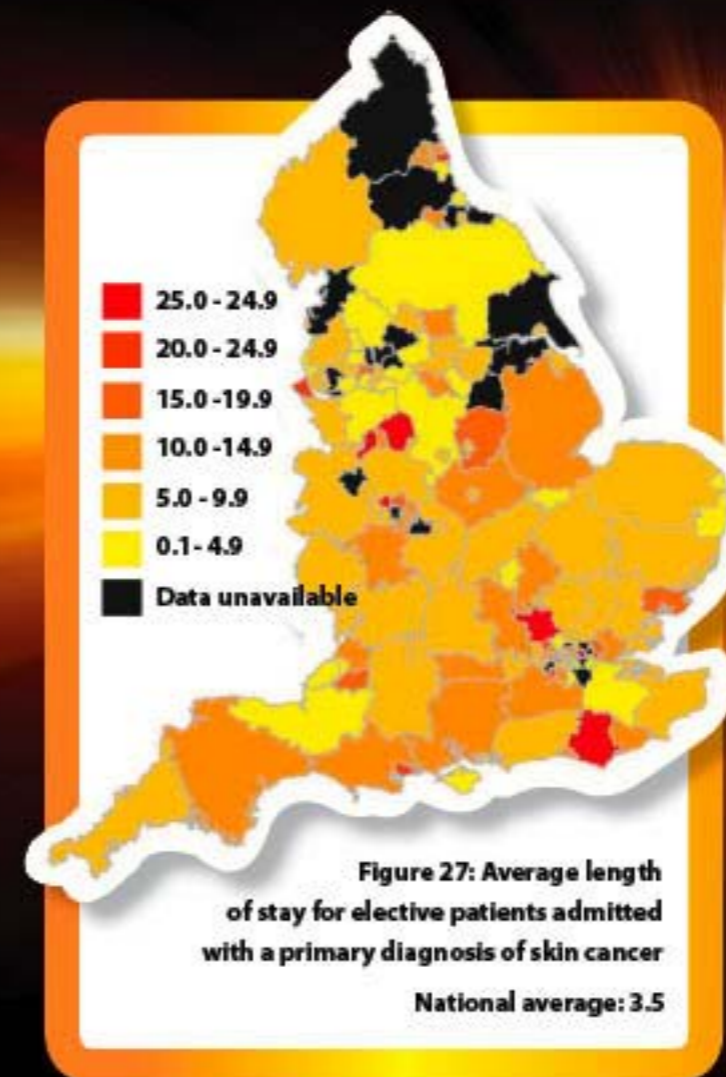
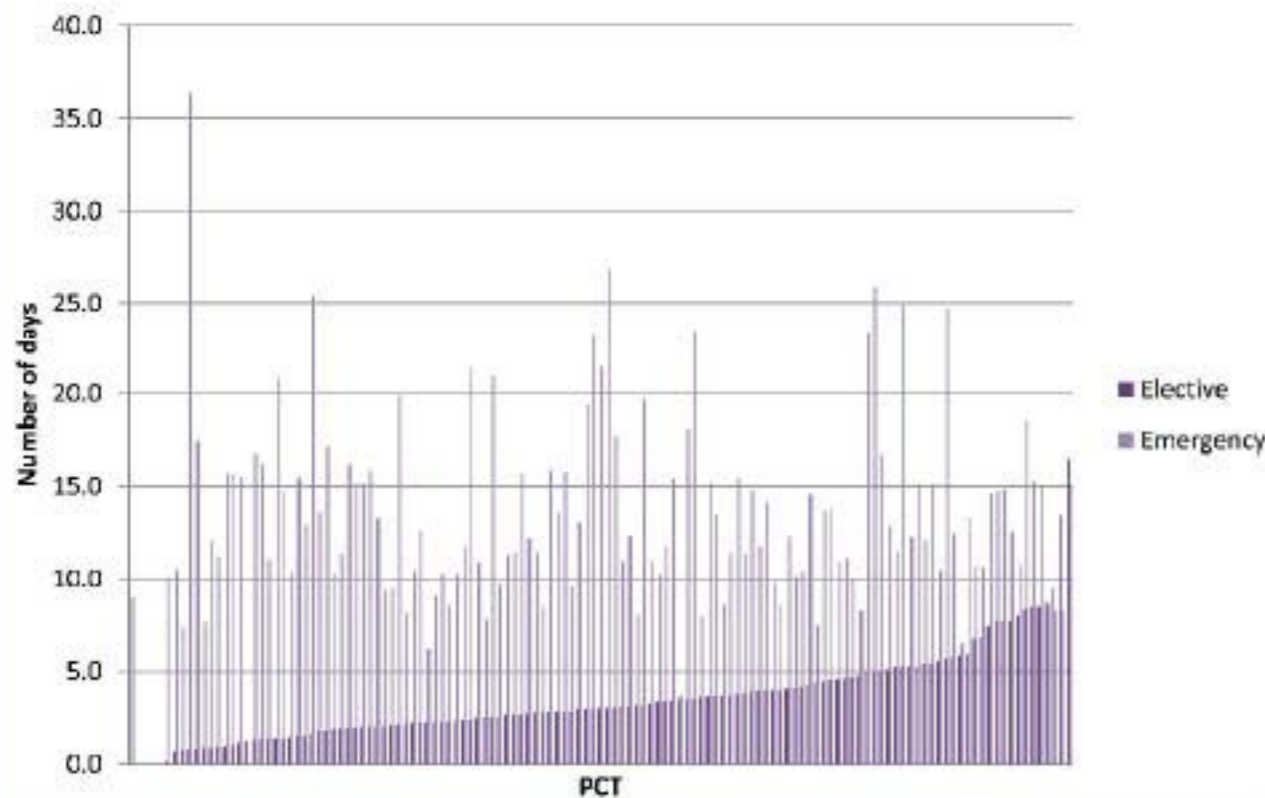


Figure 27: Average length of stay for elective patients admitted with a primary diagnosis of skin cancer
National average: 3.5

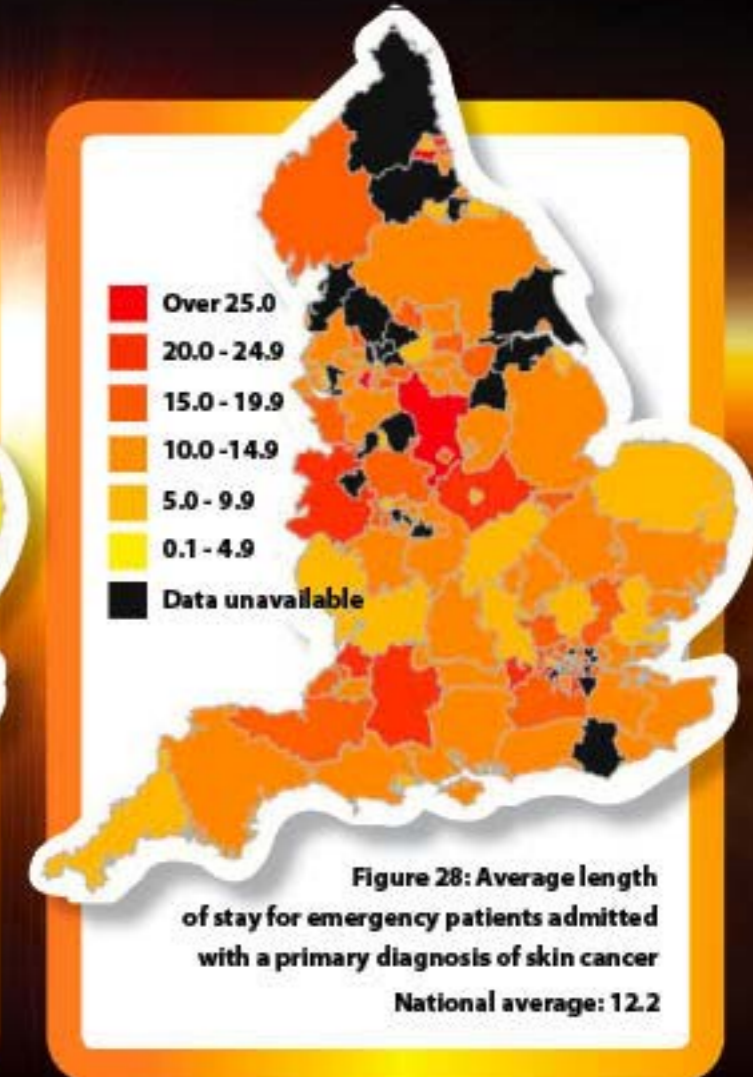


Figure 28: Average length of stay for emergency patients admitted with a primary diagnosis of skin cancer
National average: 12.2

Figures 27 and 28 show significant variation around the country in terms of the average length of stay for elective and emergency skin cancer patients. For elective surgery, patients in NHS Rotherham had the shortest length of stay, at one day, compared to 16.5 days in NHS Hertfordshire, against a national average of 3.5 days. For emergency cases, length of stay ranged from 36 days in NHS Trafford to four days in NHS Camden. On average, patients admitted as an emergency were in hospital for 12 days after treatment. Given that individuals will respond differently to surgery whether admitted as elective or emergency patients, and that some patients will experience complications and require a longer period of recovery in hospital, some degree of variation in length of stay is inevitable. However, providers can help to mitigate variations and improve overall performance, by drawing on principles of good practice - both in terms of the overall provision of care, and the process of discharge itself.

It will be important for providers with longer hospital stays to review their processes, and put measures in place to

reduce length of stay where possible and appropriate for the patient. For example, the enhanced recovery programme (ERP) is an initiative designed to minimise the stress responses on the body during surgery in order to support earlier recovery for patients, a reduced in-patient stay and a faster return to normal activities. The benefits of the ERP are improved patient experience, reduced length of stay and the possibility of increasing the number of patients under-going treatment by freeing up capacity¹⁴⁸.

Surgery for melanoma is not currently one of the procedures covered by the ERP, but the key components of the programme, which include early pre-operative assessment, planning and preparation and reducing the stress of the operation, are more difficult to achieve with emergency surgery. Providers that identify and treat melanoma patients (as elective rather than emergency patients) are better placed to streamline the patient pathway. This improves the overall patient outcome and experience as well as the cost-effectiveness of care.

Multidisciplinary teams

The NHS Cancer Plan stated that "the care of all patients with cancer should be formally reviewed by a specialist team"¹⁴⁶. Effective multidisciplinary teams (MDTs) bring together staff with the necessary knowledge, skills and experience to ensure high quality diagnosis, treatment and care. The initial focus of the MDT is a patient's primary treatment¹⁵⁰. They play a pivotal role in ensuring that patients get swift access to the best possible treatment for them, and that each individual's wider circumstances and preferences are taken into account.

The National Cancer Action Team's National Cancer Peer Review Programme 2009-10 for skin services, showed that many skin MDTs were in an early stage of development, and that inadequate MDT membership and attendance affected the majority of teams in some way⁵¹. 32 teams reported having no CNS available, in many instances because of a lack of funding or because funding had been withdrawn. A further 32 teams reported that CNS capacity affected MDT attendance and availability to support patients right across the pathway.

There was some variation in the degree to which the local skin MDT and specialist skin MDTs demonstrated that they were using effective systems for providing co-ordinated care to individual patients, as demonstrated in Figure 29. Meanwhile, a majority of MDTs were unable to show that they were continuously improving their service including both clinical effectiveness and the patient experience, as shown in figure 30.

Figure 29: Percentage of MDTs that demonstrated they had effective systems for providing coordinated care to individual patients

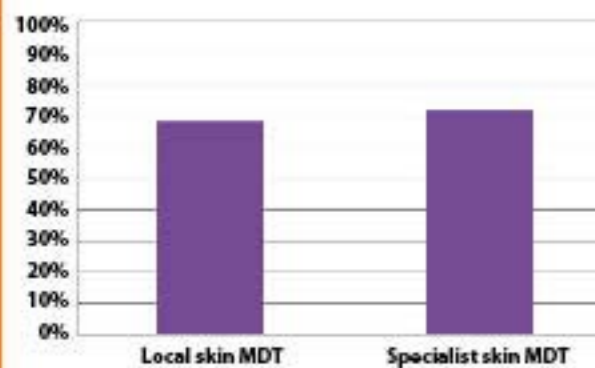
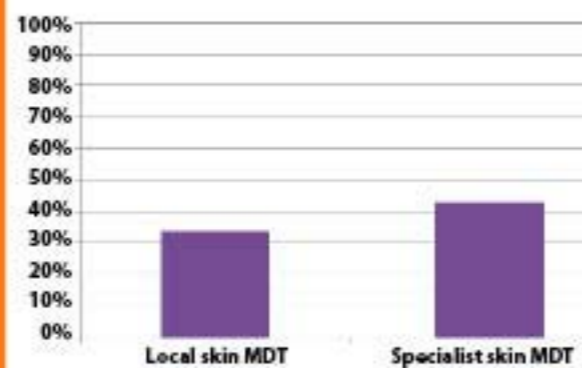


Figure 30: Percentage of MDTs that demonstrated they had continuously improved their service including both clinical effectiveness and the patient experience



As demand on services rises, commissioners will need to plan capacity and support the future development of skin cancer MDTs in line with best practice. This will be crucial to ensure that patients can benefit from the expert input of the MDT in a timely way to support high quality, patient-centred decision making.

Recommendation 6: NICE should review new treatments for advanced melanoma using the agreed criteria for end of life treatments

Recommendation 7: Clinical Commissioning Groups should ensure that patients can access treatments that are recommended by NICE in line with the NHS Constitution and patients should be able to appeal to the NHS Commissioning Board when this duty is not upheld

Recommendation 8: Cancer Drugs Fund clinical panels should regularly review the evidence for the inclusion of new treatments for melanoma, so that clinicians can access the treatments they feel will benefit their patients in a timely way

Recommendation 9: The NHS Commissioning Board should develop a commissioning plan to support the delivery of effective molecular diagnostic testing through centres of excellence

Recommendation 10: Providers should where possible follow the principles of the enhanced recovery programme to improve the experiences and outcomes of patients, and improve the efficiency of surgery

Recommendation 11: Clinical Commissioning Groups should ensure that they plan capacity effectively to accommodate an increase in demand for services, including the support of MDTs to provide high quality expert input to the treatment and care of all skin cancer patients



IMPROVING QUALITY OF LIFE AND PATIENT EXPERIENCE

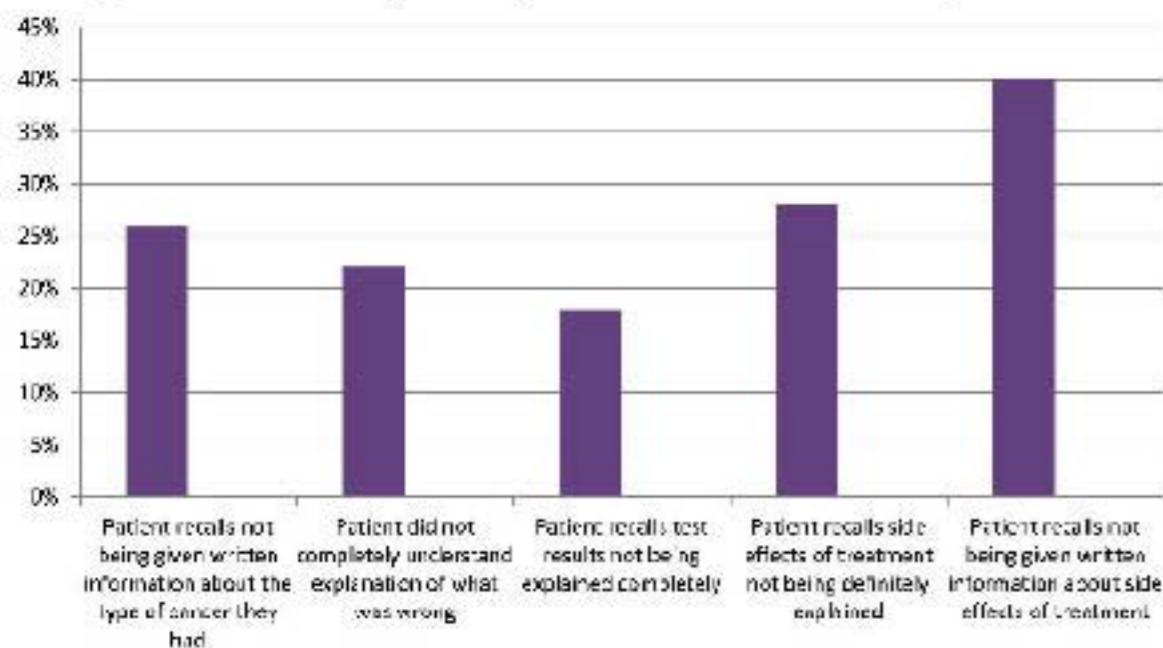
Skin Cancer UK has welcomed the recognition that a high quality patient experience is an outcome in itself¹⁵³. This chapter explores the information which is available on the experience and quality of life of cancer patients.

Patient experience

There is now comprehensive information available on the experience reported by cancer patients, including those with melanoma. More than 67,000 patients participated in the 2010 survey, including 1,322 skin cancer patients¹⁵⁴. Some data for melanoma patients have been made available at a provider level, enabling a detailed picture to be developed of experience across all aspects of the patient pathway.

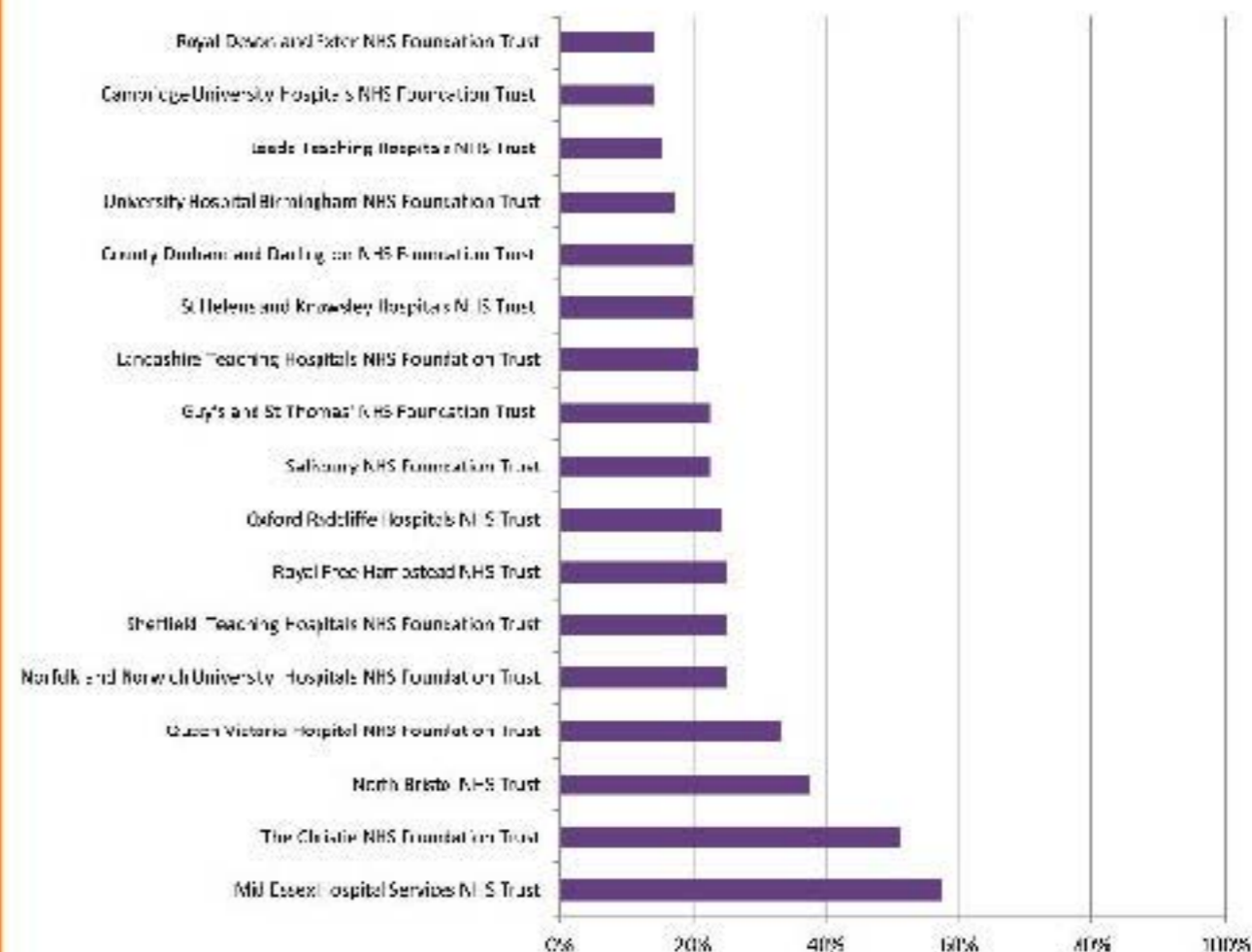
Figure 31 shows the experience of melanoma patients in relation to information provided to them. It illustrates that on the whole there is scope for improvement. It is, for example, concerning that only 60% of melanoma patients reported being given written information about the side effects of treatment¹⁵⁴. This is particularly concerning because treatments for metastatic melanoma can result in significant side effects, which can be managed, but only if patients are aware of them and know when to seek help.

Figure 31: How melanoma patients reported access to information on diagnosis and treatment¹⁵⁵



Furthermore, the national result masks large variations between providers, as demonstrated in figure 32. Only 42.9% of melanoma patients in Mid Essex Hospital Services NHS Trust recalled being offered written information about the type of cancer they had compared to the best performing trusts on this question (Cambridge University Hospitals NHS Foundation Trust and Royal Devon and Exeter NHS Foundation Trust), where 85.7% of patients said that they received written information on their cancer¹⁵⁶.

Figure 32: Percentage of providers where patients did not recall being offered written information about their cancer¹⁵⁷



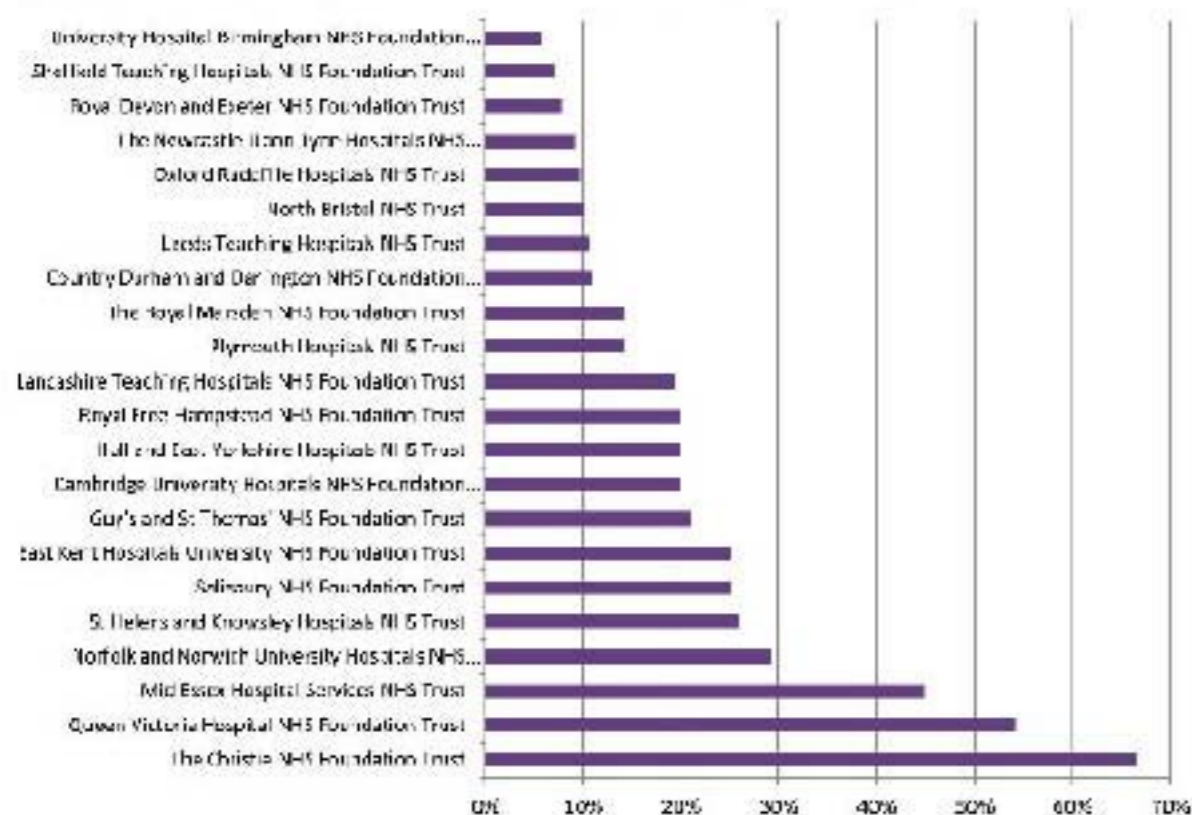
Improving the malignant melanoma patients' experience

Although the findings of the NCPES suggest that many patients have a positive experience of their treatment and care, there is clear room for improvement and the data generated from the 2010 survey must be used as the basis for doing so.

The survey made clear the critical importance of clinical nurse specialists in ensuring that patients have a positive experience of treatment and care. Patients who reported that they had access to a clinical nurse specialist also reported a more positive experience of other aspects of their care, such as access to verbal and written information, information on financial support and prescriptions, discharge information and post-discharge care, and emotional support¹⁹⁰. This is because clinical nurse specialists have in-depth knowledge of the physical, psychological and social effects of a specific condition and play an integral role in the management of patient care.

However, access to cancer CNSs varies both geographically and by tumour site, leading to inequalities in patient experience as the patient experience survey found. 75% of melanoma patients participating in the survey reported that they were given the name of a clinical nurse specialist who would be in charge of their care, below the average for all tumour types, 84%¹⁹⁰. Again, however, this masks substantial variations between providers as figure 33 illustrates. At the Christie NHS Foundation Trust, only 33.3% of patients said that they were given the name of the clinical nurse specialist in charge of their care, compared to 81.5% of patients for all tumours¹⁹⁰. In contrast, at University Hospital Birmingham NHS Foundation Trust, 94.1% of melanoma patients reported that they were given the name of a CNS¹⁹¹.

Figure 33: Patient was not given the name of the clinical nurse specialist in charge of their care¹⁹²



That patients should have access to a clinical nurse specialist is not a new concept.

Improving Outcomes for People with Skin Tumours, published in 2006, recommends that:

*"Each Local Skin MDT and Specialist Skin MDT 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"*¹⁹³.

Improving Outcomes for People with Skin Tumours also recommended that patients should be invited to bring someone with them to their consultation. The NCPES, found that on average only 60% of skin cancer patients were told they could bring a family member or friend with them when they were first told that they had cancer, the lowest of all tumour types¹⁹⁴.

It should be noted that the survey also contains useful anecdotal feedback from patients, some of which is concerning.

For example, one melanoma patient reported:

*"The way I was told was appalling - a copy of the letter which had been sent to my GP. It then took 10 weeks before my op despite being told several times it would be 2-3 weeks. It took over 2 weeks to get my first appointment after receiving the diagnosis which I didn't fully understand. Getting info from the NHS is like getting blood out of a stone - the only helpful people were the cancer helpline at the hospital. I only found out about them because I looked in the phone book"*¹⁹⁵.

The survey also asked patients whether they recalled being offered a choice of treatment. As discussed in the previous chapter, choice of treatment for melanoma patients has, until recently been very limited. Unfortunately these data are not available at an MDT level, however 79% of melanoma patients said that they were offered a choice of treatment¹⁹⁶.

Recommendation 12: All providers should critically appraise the findings of the National Cancer Patient Experience Survey and act to address any weaknesses identified. Verbatim feedback should be used to add colour to numerical findings

Recommendation 13: Commissioners should use the information in the National Cancer Patient Experience Survey as the basis for incentivising providers to improve the quality of care they deliver through the CQUIN framework

EXPENDITURE ON SKIN CANCER

Information on expenditure on skin cancer is fundamental to planning high quality services. An analysis of the programme budgeting data reported by PCTs for skin cancer for 2009-10 shows there are extensive variations in the level of expenditure reported by commissioners, even when the data are standardised for age^{167, 168}.

Figure 34: Skin cancer programme budget expenditure per head of the weighted population (2009-10)^{169, 170}

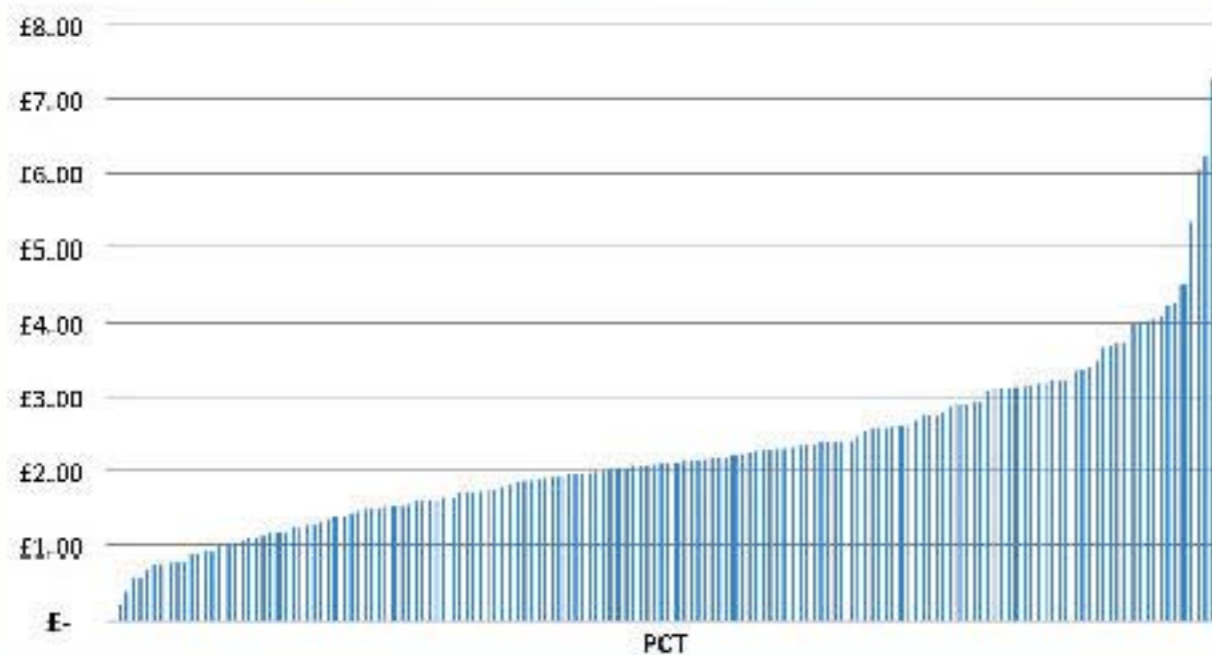
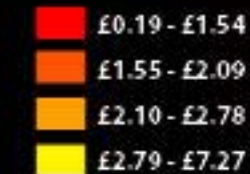


Figure 35: Skin cancer programme budget expenditure per head of the weighted population (2009-10)^{171, 172}



It is notable that expenditure is not always aligned with need, or indeed outcome. For example, NHS Cornwall reported average expenditure per capita, despite having amongst the highest levels of incidence, as shown in figure 35^{173, 174}.

These data do not cover expenditure on prevention or pre-diagnosis investigations, but do include primary and secondary care services, including prescribing expenditure. Furthermore, the National Audit Office has identified some inconsistencies in the way in which expenditure is reported, which need addressing.

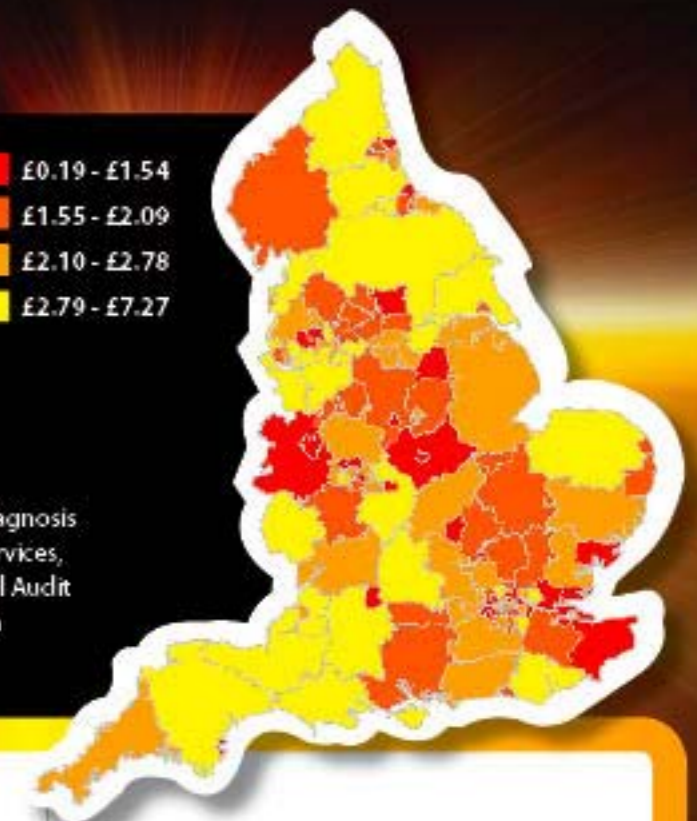
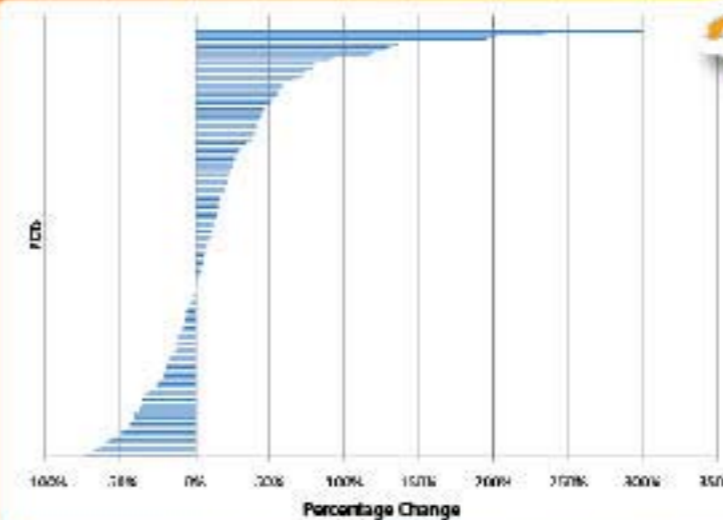


Figure 36: Percentage change in skin cancer programme budget expenditure per head of the weighted population (2008-09 – 2009-10)^{175, 176}



It is notable that 27 PCTs reported expenditure more than doubling from 2008-09 to 2009-10, while 7 PCTs reduced their expenditure by more than half over the same period as set out in figure 36.

These variations require much closer examination and we cannot draw conclusions about what they show. However, we can observe that:

- There are concerning inequalities in expenditure on skin cancer, potentially caused by inadequate or inaccurate assessments of local needs
- There may be variations in the cost and efficiency of services around the country
- There may be inaccuracies in the way that procedures are coded and expenditure is recorded, which could result in commissioners being given misleading information on expenditure

Nonetheless, programme budget data remain the best available and should be used by commissioners in planning future requirements.

It is therefore clear that we need to introduce additional scrutiny, prioritisation and incentives within the system, to support commissioners to plan and deliver services in a robust way. Commissioners also need support and guidance to fulfil their duty to secure high quality and cost-effective services on behalf of the local population.

Recommendation 14: Commissioners reporting a significant fluctuation in expenditure on skin cancer should critically appraise the reasons for this and should publish explanations in their annual reports

Recommendation 15: Commissioners which are outliers in terms of reported expenditure should assess whether the level of funding they are allocating to skin cancer is appropriate

USING DATA TO SUPPORT EFFECTIVE COMMISSIONING

A primary use of information on health needs and the quality of services should be to inform strong commissioning, with the intention of improving outcomes and ensuring efficient expenditure.

Using data to focus on outcomes improvements

The Government has published a series of outcomes frameworks for public health, NHS and social care services in either draft or final form, which set out the high level outcomes against which services will be assessed^{177, 178, 179}. These should be a key focus for commissioners and will require access to data in order to assess progress. The table right shows how improving services for people with skin cancer will make an important contribution to delivery of the domains contained in the each framework.

FRAMEWORK	DOMAIN	DOMAIN NUMBER	SUPPORTED BY GOOD QUALITY CARE FOR PATIENTS WITH SKIN CANCER
PUBLIC HEALTH	Helping people to live healthy lifestyles	3	Awareness about the risks associated with over-exposure to the UV radiation to reduce the incidence of skin cancer
	Reducing the number of people living with preventable ill health	4	Prevention and awareness raising about the signs and symptoms to reduce incidence/increase early detection and improve prognosis
	Preventing people from dying prematurely	5	Ensuring that patients are diagnosed early and can access appropriate treatment to increase relative survival
NHS	Preventing people from dying prematurely	1	Good quality care for melanoma patients to support earlier detection, access to the best treatment and improved survival
	Enhancing quality of life for people with long-term conditions	2	Patients with melanoma being well supported to manage their condition through access to appropriate advice and care
	Helping people to recover from episodes of ill health or following injury	3	Increase in the proportion of skin cancer patients admitted as elective rather than emergency cases, reduced length of stay
	Ensuring people have a positive experience of their care	4	High quality information, support and treatment for patients with skin cancer to improve their experiences of care
	Treating and caring for people in a safe environment and protecting them from avoidable harm	5	Ensuring that care and treatment for skin cancer patients is provided safely to reduce the incidence of medication errors causing serious harm
SOCIAL CARE	Social care-related quality of life	1	Skin cancer patients can access effective care services when they need to, to help them maintain a working, family and social life
	Delaying and reducing the need for care and support	2	Providing effective emotional and psychological support to enable patients to live independently
	Ensuring that people have a positive experience of care and support	3	Ensuring carers feel involved in decisions about the person they care for

Applying outcomes measures to improving quality

It will also be important for commissioners to identify proxy measures for outcomes to enable real time measurement. For example, for Domain 1 of the NHS Outcomes Framework, proxy measures should include:

- Patients diagnosed at stage 1 and 2 as a proportion of cancers diagnosed
- Patients diagnosed following emergency presentation
- Patients referred for urgent investigation
- Proportion of patients referred for urgent investigation subsequently diagnosed with skin cancer
- Active treatment rate
- Access to NICE-approved treatments

One mechanism for identifying and measuring key quality measures will be through NICE quality standards. Given the historic lack of effective interventions for some areas of the patient pathways, it will be important that NICE prioritises the development of a quality standard for skin cancer.

Incentivising improvements in quality

Data should also be used to incentivise improvements in quality. A range of incentives should be used, including:

- The Commissioning Outcomes Framework which will be used to reward improvements in outcomes delivered by commissioners
- The Commissioning for Quality and Innovation (CQUIN) payment framework, which will be used to reward improvements in quality delivered by secondary care providers
- The Quality and Outcomes Framework rewards GPs for their role in providing high quality care

Ensuring commissioning is based on expert input

Cancer networks have played an important role in improving services and should now focus on ensuring commissioning is informed by appropriate multidisciplinary expertise. Evidence suggests that four in five GPs believe that clinical commissioning groups will need specialist support if they are to commission cancer services effectively¹⁰⁰. The role of networks should include identifying and applying data to improve the quality of services¹⁰¹.

Recommendation 16: NICE should develop the proposed quality standard on skin cancer as a priority and should consider developing a dedicated quality standard on malignant melanoma

Recommendation 17: The Public Health and NHS Outcomes Frameworks for 2011-12 should include measures to improve outcomes in skin cancer covering prevention, early detection and effective treatment and management

Recommendation 18: A range of incentives should be developed to support commissioners in improving the quality of care for skin cancer

Recommendation 19: Cancer networks should provide expert advice to commissioners. In order to ensure that appropriate advice is available on skin cancer, networks should include melanoma specific reference groups

CONCLUSION

Good quality and accurate information will be critical to improving skin cancer outcomes by helping to ensure that:

- Commissioners are able to make decisions on the basis of quality and plan services to meet the rising health impact of skin cancer
- Providers can learn from each other and introduce quality and efficiency improvements
- Patients can be assured that they are getting the best possible service at every stage of the pathway – including early diagnosis, treatment, care and support – and are able to make informed choices about what care they wish to receive
- The public can monitor progress in improving skin cancer outcomes

This report brings together much of the information which exists on skin cancer, enabling a critical appraisal of the variations which can occur between different areas of the country. It is now for commissioners, providers, patients and policy makers to use these data as part of their efforts to improve outcomes.



"As the number of skin cancer patients is set to rise, it is critical that NHS commissioners plan ahead to ensure that patients have access to high quality, multidisciplinary teams who are best able to plan their treatment and care. We know that access to a clinical nurse specialist dramatically improves a patient's experience of their care. High quality information and support, combined with access to the best diagnostic testing services and treatment will create new opportunities to improve outcomes and extend survival – this report tells us, it's time to act now".

Professor Barry Powell, National Clinical Adviser for Skin Cancer, Consultant Plastic Surgeon and Member of BAPRAS

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The development of this report was supported by Roche Products. Editorial control remains with Skin Cancer UK.
R0JNKCOMM00632 / December 2011