

Skin Cancer Revealed - One Year On

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Introduction

In December 2011, Skin Cancer UK published a major report, *Skin Cancer Revealed*¹, outlining the true picture of skin cancer in England. With rates of diagnosis of skin cancer rising and mortality rates from the disease quadrupling in 30 years², the report provided a timely assessment of the need for high quality services for preventing, diagnosing and treating skin cancer across the country. Since our last report, incidence and mortality rates have risen further, making it more important than ever that our recommendations are implemented to improve the prevention, diagnosis and treatment of skin cancer.

We published our last report in the knowledge that the availability of high quality, up to date data is a key driver of quality, by shining a spotlight on performance, empowering patients and campaigners to demand better care, and identifying where improvements are required. One year on, this short report gives an update on the progress that has been made in the last 12 months on some of the elements of service provision that matter most to patients with skin cancer. At a time of significant change for the NHS, it is important to revisit the arguments and recommendations set out in *Skin Cancer Revealed* to maintain a clear focus on improving the quality of care. We urge the NHS to continue implementing the recommendations we made in *Skin Cancer Revealed*; in this report we have added to our recommendations to highlight areas where particular improvement is required.

Given the increasing numbers of people with skin cancer in England, it is vital that there is renewed focus on the challenges ahead so that together, patients, healthcare professionals, commissioners and the Government can deliver the changes that are needed to make a difference to the lives of everyone affected by skin cancer.

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Our new recommendations

Incidence and outcomes

- Health and wellbeing boards should evaluate local incidence, mortality and survival rates to inform development of their joint strategic needs assessments and their local health and wellbeing strategies
- Commissioners should routinely benchmark local mortality and survival rates against their peers
 and consider what service changes are required throughout the pathway to ensure they are
 among the best performers

Prevention services

- Public Health England should develop its role as a central data hub to ensure local commissioners understand the needs in their areas and use this as the basis of their allocation of public health resources
- Local authorities should improve co-ordination of prevention activities across public health, education and social care services
- Health and wellbeing boards must undertake robust joint strategic needs assessments and develop health and wellbeing strategies to underpin strong local commissioning of prevention services

Access to early diagnosis services

- Commissioners need to identify innovative ways to deliver screening programmes, including through occupational health services
- Access to diagnostic testing in primary care needs to be improved so that GPs can quickly identify those patients who need to be referred
- Trusts should publish data on skin cancer conversion rates (the number of patients diagnosed as
 a proportion of the number of patients referred) to help to identify which GPs are potentially
 under-referring. Publication of these data should encourage GPs to critically appraise their
 referral practices

Access to treatments

 Assessments of the implementation of the NICE guidance on the new treatments for malignant melanoma should be included in the innovation scorecard to measure NHS progress in incorporating new guidance

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- Commissioners should measure the performance of providers in offering patients clinically appropriate tests and treatments in line with current clinical guidance
- The NHS Commissioning Board should work with relevant stakeholders to develop an appropriate model for the delivery of high quality diagnostic testing in the NHS

Improving patient experience

- Providers should assess the findings of the National Cancer Patient Experience Survey to benchmark their performance and act swiftly to address weaknesses. Year on year improvement in the responses should be expected as the norm
- Commissioners should use data from the National Cancer Patient Experience Survey to assess
 providers' performance, to make clear their expectations of improvements and to develop
 incentives for providers to improve the quality of the care that they deliver
- Clinicians should be supported through medical training to develop the skills required to underpin shared decision-making in practice

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Incidence and outcomes

Incidence

A reminder of our last report:

In *Skin Cancer Revealed* we highlighted the increasing incidence of malignant melanoma, with more than 9,000 cases reported in 2008. The report highlighted differences in rates of melanoma across the country, with almost an eightfold variation between the highest and lowest rates in England³.

It is extremely concerning that the number of people diagnosed with melanoma has continued to rise since our last report. In 2010, there were 12,818 new cases of melanoma in the UK⁴ (compared to the 9,695 reported in 2008). Figure 1, below, demonstrates the continuing upward trend in the incidence of melanoma.

Figure 1: Malignant melanoma incidence rates per 100,000 population, UK, 1975-2010⁵



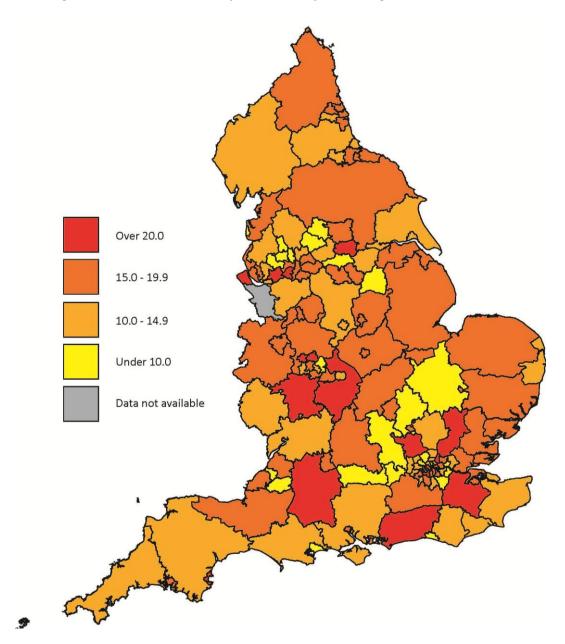
Incidence of melanoma for both men and women has increased more rapidly than for any of the ten most common cancers⁶. This trend in incidence is set to continue, with the number of new cases of malignant melanoma in England projected to increase by 88% in men and 66% in women by 2020⁷. There are a number of reasons for the continuing upward trend, but it is crucial that swift action is taken to implement our recommendations to minimise the impact of these changes.

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Skin Cancer Revealed⁸ highlighted wide variations in the incidence of malignant melanoma between PCTs in England. We previously highlighted almost an eightfold variation in incidence between the highest rate in Plymouth Teaching PCT and the lowest in NHS Newham in London. Although it can take time for the results of prevention efforts to be realised, it is nonetheless disappointing that our updated analysis shows that local variations persist and that there is now close to a nine-fold variation between the highest and lowest rates. Figure 2 below, shows the distribution of melanoma incidence from 2007 to 2009⁹.

Figure 2: Malignant melanoma incidence per 100,000 by PCT in England (2007-2009)



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As in our previous report, NHS Newham has the lowest incidence rate (3.0 cases per 100,000); the highest rate is now seen in NHS Oxfordshire (26.2 cases per 100,000)¹⁰. This ongoing variation highlights the importance of local action to understand and develop services that respond to local need.

Outcomes

A reminder of our last report

In 2011, we set out details of the mortality rates for melanoma, with 1,725 deaths due to melanoma in England in 2008. We also highlighted the wide variation in mortality rates between different primary care trusts, with a five-fold variation evident between the highest and lowest rates¹¹.

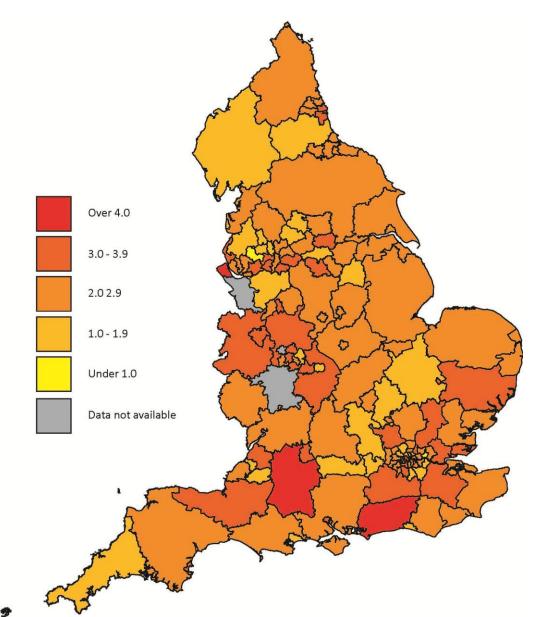
There has been a continuing upward trend in mortality from malignant melanoma since *Skin Cancer Revealed* was published. In 2010, there were 2,203 deaths from malignant melanoma (compared to 1,725 in 2008), accounting for around 1% of all deaths from cancer¹². Since our last report was published, the average mortality rate of 2.6 deaths per 100,000 in each PCT has stayed the same. However, the significant variation between different areas has persisted¹³.

As in our previous report, NHS Plymouth Teaching PCT had the highest mortality rate (4.3 deaths per 100,000 of the population), which is likely to be linked to the relatively high incidence of melanoma in the area (the third highest rate in the country). However, high mortality rates cannot only be explained by relatively high incidence rates; mortality in NHS Tower Hamlets was also in the upper quartile with 3.3 deaths per 100,000 despite an incidence rate of 9.9, well below the national average of 16.0¹⁴. In contrast, NHS Western Cheshire, which had one of the highest incidence rates in country, at 24.6 per 100,000, had a mortality rate of only 2.3 per 100,000. These variations are set out in Figure 3, below.

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Figure 3: Malignant melanoma mortality per 100,000 by PCT (2007-09) 15



As we highlighted in *Skin Cancer Revealed* ¹⁶, these data demonstrate the urgency of local commissioners understanding not only the incidence of melanoma in their area but also the services that are required to respond to this. Throughout the pathway, from prevention and diagnosis to treatment and beyond, commissioners will need to understand the challenges they face in designing services for their local population.

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Our new recommendations:

- Health and wellbeing boards should evaluate local incidence, mortality and survival rates to inform development of their joint strategic needs assessments and their local health and wellbeing strategies
- Commissioners should routinely benchmark local mortality and survival rates against their peers and consider what service changes are required throughout the pathway to ensure they are among the best performers

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Prevention services

A reminder of our last report

Skin Cancer Revealed set out the major role played by over-exposure to UV light as the main preventable cause of skin cancer. We included recommendations for Public Health England to take action to improve awareness of the causes of skin cancer, particularly among high risk groups¹⁷.

As we have set out above, the incidence of melanoma is continuing to rise in England, which means greater efforts are required to improve prevention services, including outside the NHS. Improving prevention will be an important test of the effectiveness of the new public health system, and the ability of the new arrangements to drive a more integrated approach to planning and delivering services.

Skin Cancer Revealed included a recommendation for Public Health England (PHE) to 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 level¹⁸. This recommendation should still be implemented. In addition, PHE should use its role as a central hub for public health data and intelligence to provide the basis for local decisions about commissioning of skin cancer prevention services. PHE will incorporate existing cancer registries, the National Cancer Intelligence Network and public health observatories¹⁹. As a consequence, PHE will have a major role in supporting local commissioners to understand local need, which should inform the allocation of appropriate resources for community-based sun safety campaigns and education initiatives.

As the new public health structures take shape at a local level there are other actors who will play a role in delivering improved prevention services:

- Local authorities will have a key role in designing, commissioning and performance managing
 prevention services. They will need to use their expertise and oversight to be able to join up the
 prevention efforts of local education and social care services with NHS provision
- Local health and wellbeing boards are responsible for developing joint strategic needs assessments (JSNAs) and health and wellbeing strategies, which should underpin local commissioning plans, this must include assessment of skin cancer prevention
- Membership of health and wellbeing boards will include representatives of different organisations and sectors. Boards should take this opportunity to support the development of an overarching approach incorporating wider services that have an impact on health and wellbeing including in schools, the workplace and public spaces

Our new recommendations:

- Public Health England should develop its role as a central data hub to ensure local commissioners understand the need in their areas and use this as the basis of their allocation of public health resources
- Local authorities should improve co-ordination of prevention activities across public health, education and social care services

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Access to early diagnosis services

A reminder of our last report

Skin Cancer Revealed highlighted the importance of early diagnosis for improving survival rates for melanoma. We also stressed the importance of ensuring that patients with suspected melanoma had swift access to diagnostic testing and specialist teams when they do approach health services²⁰.

Patients diagnosed with early stage malignant melanoma (stage 1A), have a good prognosis with five year survival at 95%²¹. However, a fifth of patients are diagnosed with advanced disease²² when melanomas have spread to nearby lymph nodes (stage 3) or another site in the body (stage 4).

Swift referral from general practice is crucial to improving early diagnosis and survival rates. We have assessed the information contained in the *National Cancer Patient Experience Survey*²³ about how many times patients visited their GP before they were referred. Our analysis of the most recent survey data shows that:

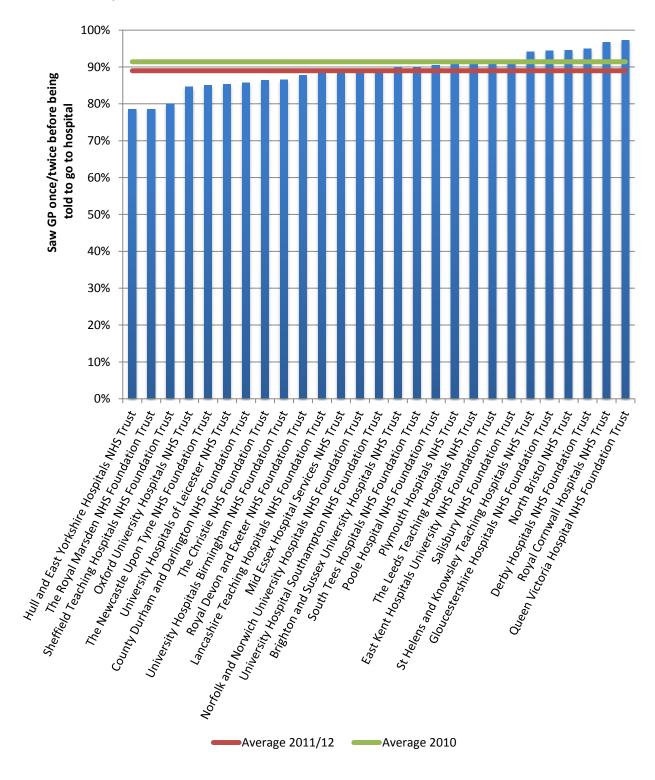
- The proportion of skin cancer patients that saw their GP more than twice before going to
 hospital has increased 11 per cent of skin cancer patients were required to make three or
 more visits in 2011/12²⁴, compared to the 9 per cent we highlighted in Skin Cancer Revealed²⁵
- With over 10,600 people diagnosed with skin cancer each year in England, this equates to almost 1,200 patients facing delays before receiving hospital care²⁶
- There is significant regional variation in the performance of trusts; for trusts where there were sufficient numbers of respondents with skin cancer to enable robust comparisons, the proportion of patients who saw their GP less than three times before being referred ranged from 78.6 per cent to 97.2 per cent²⁷. These variations are set out in Figure 4 below

These results suggest that opportunities to identify cancer in primary care are being missed. Greater efforts are needed to identify which GPs are not referring appropriately and the data available through the *National Cancer Patient Experience Survey* and the National Cancer Intelligence Network need to be used to benchmark performance in primary care. In addition, there is a need to improve access to diagnostic testing within primary care so that GPs are able to identify which patients need to be referred rapidly through the urgent referral pathway.

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Figure 4: Proportion of skin cancer patients that visited their GP once or twice before being referred to hospital²⁸



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Beyond general practice, occupational health services can have a significant role in identifying skin cancers. Many people will be exposed to the risk of skin cancer through their work, for example those who work outside. Even where this is not the case, providing awareness and screening services within the workplace can increase the early diagnosis of skin cancers. Local commissioners should consider new ways of delivering screening programmes, including through occupational health services. By assessing thoroughly their local need and capacity they will be able to commission innovative services accordingly.

Our new recommendations:

- Commissioners need to identify innovative ways to deliver screening programmes, including through occupational health services
- Access to diagnostic testing in primary care needs to be improved so that GPs can quickly identify those patients who need to be referred
- Trusts should publish data on skin cancer conversion rates (the number of patients diagnosed
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Access to treatments

A reminder of our last report

In *Skin Cancer Revealed*, we described how treatment options for patients with advanced or metastatic had historically been limited and, although advances in surgical techniques had improved survival rates and outcomes for patients, much of the efforts to improve survival remained focused on prevention²⁹.

Since our last report, the National Institute for Health and Clinical Excellence (NICE) has issued guidance recommending the use of two new treatments for advanced melanoma^{30,31}. It is extremely welcome that these medicines should be routinely available through the NHS for patients in England and Wales. This guidance must be implemented swiftly across the country to ensure that all eligible patients have prompt access to these new treatments no matter where they live.

The NHS Constitution makes it clear that all patients have the right to access medicines and technologies recommended by NICE for use in the NHS if a clinician feels they are clinically appropriate³². Despite this entitlement, compliance with NICE guidance has been an enduring problem for the NHS and serves as a barrier to the delivery of high quality care. Since our last report there have been a number of initiatives that were intended to improve uptake of NICE guidance:

- The NHS Chief Executive's *Innovation, health and wealth* review identified the need to reduce variation in the NHS and drive greater compliance with NICE guidance as a clear priority³³
- The Health and Social Care Information Centre has published an 'innovation scorecard' providing data on the uptake of 48 medicines associated with 79 technology appraisals³⁴ enabling comparison between different organisations' rates of implementation
- From April 2013, all NHS organisations will be required to publish information on which NICE technology appraisals are included in their local formularies³⁵. However, research shows that only a third of PCT clusters have communicated with local formulary committees about the policy to speed up adoption of NICE recommended treatments³⁶

The NHS Commissioning Board has an important role in monitoring the uptake of NICE approved treatments, including those for metastatic malignant melanoma, across the country, and identifying areas where uptake is below anticipated levels. In addition, data on treatments should be available to support patients to make choices about where to receive their care. We would, therefore, like to see statistics on the uptake of the NICE approved treatments for melanoma included in future iterations of the innovation scorecard.

Skin cancer patients are increasingly able to benefit from targeted therapy, that is treatment tailored to the particular biological characteristics of their cancer. These treatments help smaller cohorts of patients within a specific tumour classification. To realise the benefits of targeted skin cancer treatments, it is crucial that the right testing infrastructure is in place to identify eligible patients in a timely way.

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However, the quality of testing services can vary across the country, which will become a more serious challenge for the NHS as the pace of development in targeted medicine accelerates³⁷. It is imperative that the Department of Health takes steps to establish a sustainable NHS molecular diagnostics service to ensure that every patient is in a position to benefit from advances in personalised medicines as soon as possible.

Our new recommendations:

- Assessments of the implementation of the NICE guidance on the new treatments for malignant melanoma should be included in the innovation scorecard to measure NHS progress in incorporating new guidance
- Commissioners should measure the performance of providers in offering patients clinically appropriate tests and treatments in line with current clinical guidance
- The NHS Commissioning Board should work with relevant stakeholders to develop an appropriate model for the delivery of high quality diagnostic testing in the NHS

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Improving patient experience

A reminder of our last report

Skin Cancer Revealed provided an overview of the variations in patients' experience of their care, drawn from the 2010 *National Patient Experience Survey*. We recommended that NHS providers use the data from the survey to assess and improve their services³⁸.

Since our last report was published, the results of the 2011 *National Cancer Patient Experience Survey* have been made available, which included responses from 1,695 patients with skin cancer³⁹. Many of the questions in the 2011 survey had previously been asked in 2010 and we have compared the results of the two surveys to assess where progress has been made in three areas:

- Providing high quality information
- Access to a clinical nurse specialist
- Shared decision-making

The following table sets out the differences between the responses for patients with skin cancer for some of the questions relating to these elements of patients' experience.

Table 1: Comparing the experience of skin cancer patients between 2010 and 2011

Question	2010 ⁴⁰	2011 ⁴¹
Information		
Patient recalled their test results being explained	82%	83%
Patient recalled being given written information about the type of cancer they had	74%	78%
Patient recalled side effects of treatment being explained in a way that they could understand	72%	74%
Patient recalled being given written information about side effects ahead of their treatment starting	60%	67%
Patient understood completely what was wrong with them	78%	79%
Access to clinical nurse specialist		
Patient recalled being given the name of a clinical nurse specialist who would be in charge of their care	75%	84%
Shared decision-making		
Patient reported their views were definitely taken into account by the team discussing their treatment	N/A	76%
Patients reported that their doctors did not talk about them as if they were not there	85%	86%

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These responses are encouraging. They show that tangible improvements are being made in patients' experience of services. However, the figures also show that across these key markers of quality around one in five patients is still not giving a positive response and this rises to more than one in four for some questions.

Providing high quality information

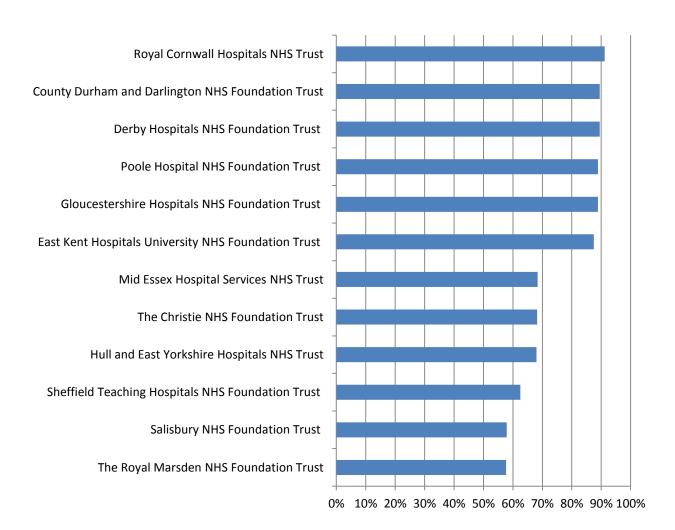
The concept of providing patients with information on which to base decisions about their care is not new. Although progress has been made in providing more patients with information, it is still important for the NHS to make efforts to ensure that what is provided is in an accessible and meaningful format.

The national level data also mask significant variations between providers. The following chart sets out the results for the trusts rated in the top 20% and bottom 20% for providing written information about the patients' cancer:

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Figure 5: Proportion of patients given written information about the type of cancer they had 42



Compared to the individual results of the 2010 survey, there has been progress in providing written information about skin cancer, but there is still a long way to go for some trusts. Ensuring that patients have sufficient information about their cancer, their treatment options and potential side effects is crucial to ensuring that patients can make decisions about their care. Supporting patients to understand their condition and know when to seek advice can help them to manage their own care.

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Access to a clinical nurse specialist

The role of clinical nurse specialists (CNSs) in supporting patients is well-documented. The *National Cancer Patient Experience Survey* has highlighted the impact they can have; in both the 2010 and 2011 surveys, patients who reported having access to a CNS were more likely to be positive about other aspects of their care than other patients⁴³. The most pronounced differences between those patients with a CNS and those without one were linked to:

- Verbal and written information
- Involvement in decision-making
- Information on financial support and prescriptions
- Discharge information and post-discharge care
- Emotional support⁴⁴

A higher percentage of skin cancer patients recalled being given details of a CNS in the 2011 survey than in 2010, 84% compared to 75%. However, this proportion is still lower than the average for all tumours types, which was 87%, and significantly lower than for breast cancer, 93%⁴⁵. These figures demonstrate that greater efforts must be made to ensure that all patients with skin cancer have access to a CNS.

Supporting shared decision-making

One of the NHS's underpinning principles is 'no decision about me without me', highlighting that patients should be at the heart of decisions about their care. In December 2012, the Department of Health published a *Choice Framework*, which set out details of the choices that patients should expect to be able to exercise during their care⁴⁶. Introducing shared decision-making will require a change in culture within the NHS so that patients and their preferences are central to the decision-making processes.

There was a new question in the 2011 *National Cancer Patient Experience Survey* about whether patients felt their views were taken into account by the team making decisions about their care. It is encouraging that skin cancer patients had the most positive result for this question: 76%, compared to a national average of 70% and results of 64% for patients with sarcoma or brain/central nervous system cancers⁴⁷.

However, this still leaves almost a quarter of skin cancer patients who did not feel their views were taken into account, which demonstrates that many services are still falling short of delivering shared-decision making. Improving patients' experience of care must be a priority for the NHS to ensure that all patients with skin cancer get the information, choices and support they need. The *National Cancer Patient Experience Survey* is a rich source of data for commissioners and providers on how individual trusts are performing and must be used more effectively to identify areas for improvement.

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Conclusion

This report demonstrates that, although progress has been made, there are still significant challenges to improving the prevention, diagnosis and treatment of skin cancer in England. Since our last report, incidence and mortality rates have continued to rise and it is vital that opportunities to reverse these trends are seized as quickly as possible.

The reform of the NHS creates an unprecedented focus on securing improvements in patient outcomes. We urge the NHS Commissioning Board and clinical commissioning groups to take action to deliver improvements in services speeding up diagnosis, throughout treatment and management and, wherever required, during care at the end of life. Long-awaited advances in treatment are already helping to extend life and improve the quality of life for people living with advanced cancer. The NHS will need to focus efforts on ensuring equity of access to these new treatments, supported by an effective and timely diagnostic testing service so that patients benefit from new targeted therapies as soon as possible. In addition, changes to public health commissioning create important opportunities to begin to co-ordinate prevention and early detection efforts more effectively in the community.

We hope that the new recommendations in this report will form the basis for this urgent discussion and will prompt action on the part of patients, professionals, providers and commissioners alike. The vast majority of skin cancers are either preventable or treatable and there has never been a better time to take action.

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This report has been developed on behalf of Skin Cancer UK by MHP Health Mandate. Funding for this project has been provided by Roche Products Ltd who review the content for factual accuracy. Final editorial control rests with Skin Cancer UK

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