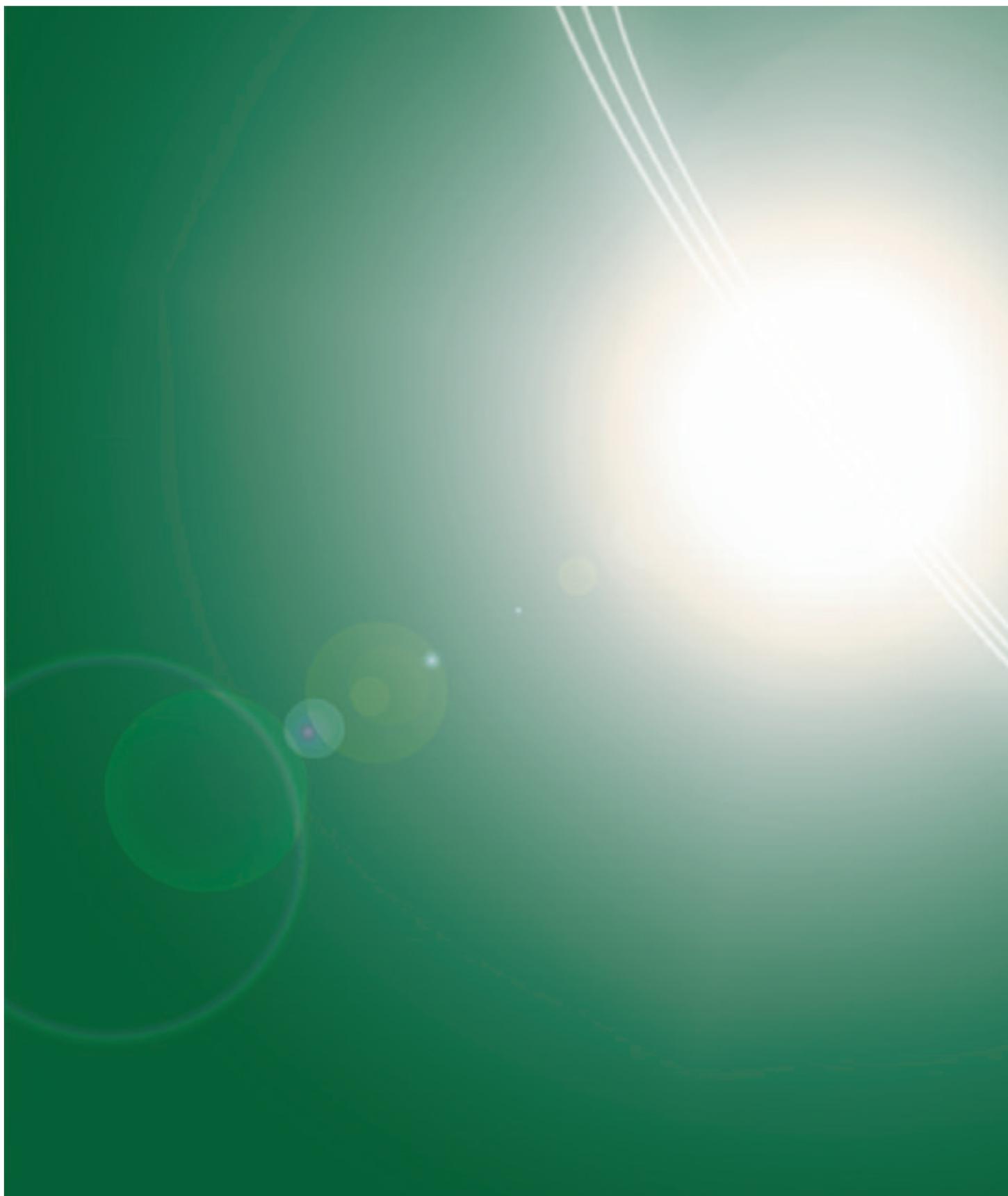


2015 Skin Cancer Visions



The Melanoma Taskforce

Chaired by Siân James MP





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Foreword by Siân James MP



Amongst the many campaigns I have been involved with since becoming an MP in 2005, one of my proudest moments came earlier this year when Parliament banned tanning salons from allowing under-18s to use sunbeds in England and Wales. Julie Morgan's Private Member's Bill was the culmination of years of campaigning with patient groups and parents to tighten the regulations on sunbed use. This legislation will help tackle the rapid increase of skin cancer in young people when it comes into force in April 2011. I hope that further restrictions in sunbed use follow but their use is only one part of the problem.

In 2007, more than 10,600 people in the UK were diagnosed with melanoma, which represents a quadrupling of the disease's incidence since the 1970s. It is a disease that can affect all types of people and all ages; melanoma is now the second most common cancer in young adults, aged between 15 and 34, and almost one third of all cases occur in people under 50. Although the disease still affects slightly more women than men, the number of men diagnosed with melanoma has doubled in the last 30 years. In 2008, over 2000 people in the UK died from melanoma and there is evidence that this figure will continue to rise as young people who have experienced sun damage through over-exposure to the sun and sunbeds have an increased chance of developing skin cancer later on in life.

The tragedy is that most of these cases are preventable, and many patients could have been treated successfully had their symptoms been detected early. That is why I have brought together the Melanoma Taskforce, an expert panel of patient groups, oncologists, dermatologists, surgeons, charities, skin cancer nurses and GPs to look again at how we can improve prevention and care for people diagnosed with all forms of skin cancer.

This report puts forward practical recommendations for policy makers in Government and the Department of Health, identifying improvements that can be made right across the melanoma patient pathway. It is vitally important that skin cancer continues to be a public health priority during a period of reform in the NHS. We have fed our recommendations into the consultations on the refreshed Cancer Reform Strategy and Health White Paper and will continue to work with the Department of Health to ensure that these issues are addressed.

It is crucial that NHS and public health leaders understand the seriousness of melanoma and, with its incidence set to continue rising, they develop strategies that not only reduce the risk for future generations, but better treat those who have already experienced skin damage and are at greater risk of developing melanoma in the future.

Siân James MP
Chair, Melanoma Taskforce



Executive summary

Introduction

This report presents the findings of an inquiry undertaken by Siân James MP and skin cancer experts into the progress made by the Cancer Reform Strategy (CRS) in meeting the 2012 Skin Cancer Visions.

The 2012 Skin Cancer Visions, developed by clinical experts at the outset of the CRS in 2007, presented a set of five year aspirations for skin cancer policy. They identified specific clinical and policy objectives that, if achieved, would improve the prevention, diagnosis and treatment of skin cancer and reduce incidence and mortality from the disease. It should be stressed that these were not formal targets, but recommendations for a Vision for skin cancer that would help inform the CRS.

In his third annual review of the CRS this year, National Clinical Director for Cancer, Professor Sir Mike Richards aims to establish a new five year cancer strategy that is aligned with the direction of healthcare reform under the new Government. To help inform this process and ensure that the revised CRS reflects the latest developments in patient care, the Melanoma Taskforce aims to present the Department of Health with its skin cancer visions for 2015.

Siân James MP submitted a joint letter from the Taskforce to the CRS Consultation that closed on 24th September, setting out the group's response to Professor Sir Mike Richards call for evidence. Many of those recommendations are included in this report which gives a more detailed summary of the group's analysis.

Melanoma Taskforce

When convening the group of skin cancer experts to undertake this review, Siân James MP drew on the recommendations of patient groups and clinicians she has campaigned with in recent years and also sought representation from leading organisations in this field, such as the British Association of Dermatologists and the Melanoma Study Group.

It was important that practitioners from each stage of the patient pathway were represented on the group, including GPs, skin cancer nurses, dermatologists, oncologists and surgeons as well those involved in data collection and policy. The group is not closed to new members and those wanting to join the Taskforce to help realise these 2015 Visions should contact Siân James MP.



Taskforce meeting

On Tuesday 14th September, Siân James MP convened the inaugural meeting of the Taskforce in Parliament to discuss which areas of skin cancer policy should be prioritised in the refreshed CRS and to draft a response to the Consultation.

Prior to the meeting, Ms James asked attendees to complete a questionnaire to get their views on the relative successes of the CRS in meeting the 2012 Visions. Respondents were asked to award a score of between 1 and 4 against each of the Visions indicating whether they felt that the objective had been:

1. Not at all achieved
2. Partially achieved
3. Achieved,
4. Exceeded the Vision

The results of the survey formed the basis for the groups' audit of the 2012 Skin Cancer Visions at the Parliamentary meeting.

Summary of findings

The 2012 Visions survey revealed that, on the whole, members of the Taskforce didn't feel that the objectives for skin cancer policy set in 2007 had been achieved. The highest average score awarded to any of the policy goals was 2.53. This was on the need for professional groups to regularly update multidisciplinary guidelines on diagnosing, staging and managing melanoma and other skin cancers. The most common response to any of the Visions was that they had been 'partially achieved'.

Taken at face value, the survey results paint the achievements of the CRS in skin cancer in a dim light. However, the group discussion at the Parliamentary meeting revealed that many advances had been made in the quality of care received by skin cancer patients, achievements that many around the table had been personally involved in realising. For example, Catherine Wheelhouse from Bradford Teaching Hospitals NHS Trust was the first skin cancer specialist nurse, and has championed the interests of melanoma nurses in Multidisciplinary Teams (MDTs) across the country through the British Association of Skin Cancer Nurses.

On the whole, the Taskforce felt that real progress had been made towards releasing some objectives, such as the implementation of the Improving Outcomes Guidance (IOG), but other areas such as skin cancer prevention and awareness had not been prioritised enough by the CRS and other public health strategies. Other aspirations, for better skin cancer screening programmes for example, that have not seen any real improvements in recent years, were found by the group not to be practicable given the resources needed for real gains in patient outcomes. Therefore the Taskforce's recommendations do not call for all of the 2012 Visions to be met. Moreover, they provide targeted calls to action on achievable objectives that will deliver better outcomes for patients by 2015.

This report looks at each of the sections of the 2012 Visions in turn, examining the achievements that have been made in the last three years and then setting out the Taskforce's Vision for 2015. These recommendations are listed in full in the report's conclusions.



Members of the Taskforce

Siân James MP	Member of Parliament, Swansea East and Chair, Melanoma Taskforce
Caroline Cerny	SunSmart Manager, Cancer Research UK
Richard Clifford	Founder, SKCIN, The Karen Clifford Skin Cancer Charity
Simon Davies	Chief Executive, Teenage Cancer Trust
Kathy Elliott	Public Health Consultant, National Cancer Action Team
Nina Goad	Communications Manager, British Association of Dermatologists
Professor Martin Gore	Medical Director, Royal Marsden NHS Foundation Trust
Dr Mark Harries	Consultant Medical Oncologist, Guys & St Thomas' NHS Foundation Trust
Dr Stephen Hayes	GP with Special Interest in Dermatology; Trustee, Primary Care Dermatology Society
Anthony Hubbard	Technical Director, SKCIN (The Karen Clifford Skin Cancer Charity)
Andrew Langford	Chief Executive, Skin Care Campaign and Chairman, All Party Parliamentary Group, Skin Cancer Inquiry
Dr James Larkin	Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust
Dr Paul Lorigan	Consultant Medical Oncologist, Christie NHS Foundation Trust
Dr Jerry Marsden	President, UK Melanoma Study Group, University Hospitals Birmingham
Professor Julia Newton-Bishop	Professor of Dermatology, Leeds University Hospital
Gillian Nuttall	Founder, Factor 50
Joy Odili	Consultant Plastic Surgeon, St George's Hospital
Professor Poulam Patel	Professor of Clinical Oncology, Nottingham University Hospitals
Saskia Reeken	Macmillan Cancer Nurse Specialist, St George's Hospital and Skin Cancer Group Chair, British Dermatology Nursing Group
Dr Dafydd Roberts	Consultant Dermatologist, ABM University NHS Trust
Catherine Wheelhouse	Clinical Nurse Specialist Skin Cancer, Bradford Teaching Hospitals NHS Trust and Chair, British Association of Skin Cancer Nurses
Martin Whitehead	Oncology Policy Manager, Bristol Myers Squibb





Taskforce findings

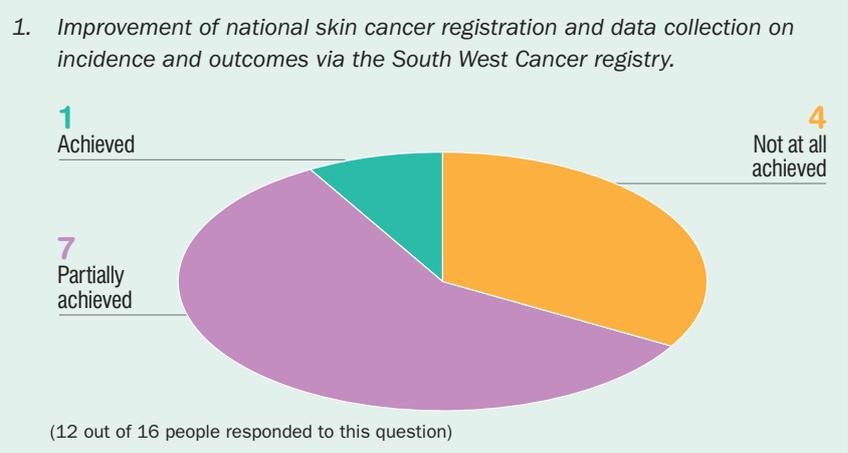
This section examines the key findings from the Taskforce’s audit of the 2012 Skin Cancer Visions and identifies which areas should be prioritised under a new CRS for 2015. Our analysis and recommendations follow the same subject headings as the 2012 Visions to cover all aspects of the patient pathway.

To ensure that the group’s recommendations provide a useful aid to the Government’s development of skin cancer policy, the Taskforce have identified those areas where:

- a. Taskforce members felt the lack of progress since the introduction of the CRS constitutes a serious cause for concern;
- b. There are examples of best practice that could be replicated across the country to improve patient outcomes;
- c. There is debate about the suitability or relevance of procedures and guidance that cause disparities in care necessitating swift resolution; and
- d. There are clear steps that can be taken to align skin cancer prevention, diagnosis and treatment strategies with the Government’s healthcare reforms in an outcomes-led NHS.

A. Epidemiology

Taskforce analysis



When asked if the 2012 Vision for data collection on skin cancer had been reached, 4 out of 12 members of the Taskforce said it had not been achieved at all and 7 said it only been partially achieved. The primary problem is that skin cancer is so common; many cancer registries have not recorded data on it routinely in the past. The National Cancer Intelligence Network (NCIN) is working to bring data collection on skin cancers in line with other tumours and aims to see progress on this by 2015.

The cancer registry and public health observatory in the South West were funded to create a ‘Skin Cancer Hub’, where all available data has been collected and used to target current prevention and early diagnosis programmes. This model has served its purpose to date, but the Taskforce felt this resource should be reviewed to consider whether it could better support future prevention and awareness strategies.



Taskforce findings continued

Members of the group stressed that the development of a data set is only the first step towards better information collection. It is also vital that all skin cancer centres across England have the resources and technology to enable them to measure and record data. Commonality of data collection is crucial to give an accurate picture of how many cases of skin cancer are being presented and at what stages.

A big challenge for the Government and the NCIN will be how data collection is monitored and incentivised. The Taskforce suggested that this could be done through the Peer Review process.

There also needs to be a two way flow of information with data being fed back to clinicians as well as funders and commissioners, who will increasingly be involved in service design under the Government's reforms of the NHS.

2015 Vision

- The NCIN should work with practitioners throughout the patient pathway to ensure universal compliance on measuring, recording and reporting to the skin cancer registry by clinicians across England. Compliance with data collection should be monitored via Peer Review.
- The NCIN should work with practitioners throughout the patient pathway to ensure universal compliance on measuring, recording and reporting data to the skin cancer registry. Compliance with data collection should be monitored via Peer Review.

B. IOG implementation

Taskforce analysis

Implementation of the IOG

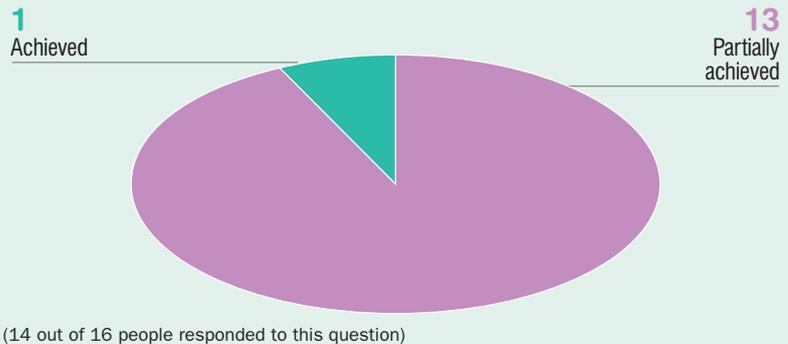
The 2012 Skin Cancer Visions set an objective for the IOG to be fully implemented by 2010. Our survey of Taskforce members found that 13 of the 14 respondents felt that this Vision had only partially been achieved (graph 2). However, graph 3 shows that on the whole, they felt that Peer Review to assess the extent of guidance implementation was taking place. This evidence would suggest that Peer Review is successfully identifying gaps in service provision but strategies to bring underperforming centres in line with best practice are not effective.

Members of the Taskforce that were involved in the development of the IOG highlighted some of the barriers they knew at the time would prevent the guidance being implemented by 2010. For example, double-reporting of pigmented lesions would not be possible because of the shortage of pathologists. However, some aspects of the guidance, like the operation of MDTs and expansion of the specialist nurse workforce have been more successfully delivered.

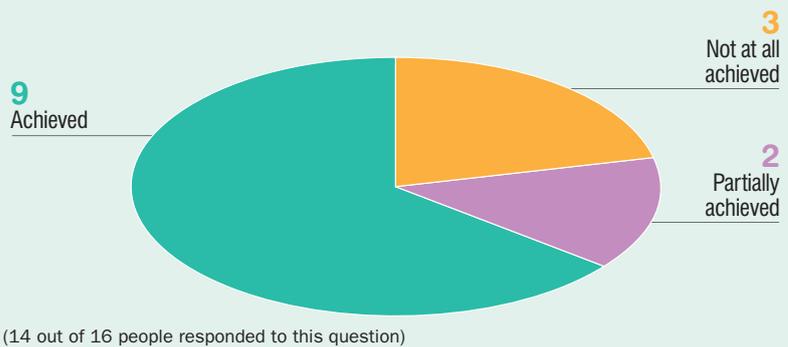
There was therefore consensus among the group that the IOG had been necessary to bring about major leaps forward in service design and improvements in the quality of care provided by local services. However, it ought to be refreshed to make it relevant and useful to commissioners and clinicians in an outcomes-led NHS. This would also provide an opportunity to revise aspirational goals in the IOG that the experience of the last four years has proven to be unworkable or unnecessary.



2. Full implementation of the IOG by 2010.



3. A national review, via peer review and Healthcare Commission assessments, to ensure that the IOG has been fully implemented across all networks.



Barriers to IOG implementation

Members of the group agreed that implementation of the IOG across England is patchy and wide variations in patient care and outcomes still exist. For example, patients treated in larger, specialist centres tend to have access to better functioning MDTs and more coordinated dermatology and oncology services compared to smaller district hospitals. It was agreed that Peer Review had been effective in identifying underperformance but should be developed so that it covers more than just the basic, minimum standards of care.

It was suggested that one of the weaknesses of the IOG to date has been the non participation of primary care in its implementation. As greater responsibility for commissioning is taken on by primary care under the Government’s forthcoming Health Bill, it will be important to define how clinicians and managers at a local level are involved in the skin cancer patient pathway and work with acute services where responsibilities overlap.

Patient outcomes

The Taskforce agreed that where it is followed, the IOG establishes the building blocks of effective skin cancer services. However, there is little evidence to show it has an impact on outcomes like patient survival; prevention and early diagnosis are still the most important factors in this respect. The IOG has put models of good practice in place but this is not an end in itself. The Taskforce was clear that the focus now must be on patient outcomes.



Taskforce findings continued

MDTs must have the flexibility to innovate and use their expertise to develop services that meet the needs of patients in their local area. It is important that the IOG is implemented in a safe, equitable, coordinated way that puts the patients at the centre of services and provides holistic and timely care.

The Taskforce felt that the inclusion of Quality Standards, including Patient Related Experience Measures (PREMs) and Patient Recorded Outcome Measures (PROMS), in a refreshed IOG on skin tumours including melanoma would provide a robust service framework and outcome goals that will guide the new commissioners of skin cancer services and give renewed focus to practitioners and MDTs.

The group was clear however, that Quality Standards in melanoma should not replace the IOG. Moreover, Quality Standards should be added to the IOG in a refreshed set of guidelines that sets out best practice but also the patient goals that centres should be geared towards delivering. These standards need to be ambitious and be set at a level that brings the worst performing providers up rather than just ensuring a minimum standard across the board.

The Taskforce agreed that survival (both one and five year) is ultimately the most important outcome for melanoma patients along with decreasing incidence and mortality. There are also other outcomes that could be used to measure improvements in patient care.

These could include:

- Stages of melanoma at presentation and diagnosis
- Availability of Sentinel Node Biopsy
- Patient experience and satisfaction
- The effectiveness of MDTs
- The proportion of patients entering clinical trials.

Melanoma has already been identified as an area where patient outcomes could be improved most by the introduction of Quality Standards. The Taskforce is keen to work with the Department of Health to bring about the swift development of these Standards, in line with our recommendations for outcome measures in melanoma.

Clinical resources and funding

The 2012 Visions survey revealed that no one felt increases in the number of specialist skin cancer practitioners and funding for skin cancer services had been achieved. Interestingly, the meeting discussion brought agreement among Taskforce members that effective working of the MDT was as important as simply the numbers of practitioners operating in each service.

Specialist skin cancer nurses have been pivotal in helping deliver the IOG and in driving up the quality of patient care. While the Taskforce is aware there is not a bottomless pit of CNSs to draw upon, the next CRS needs to ensure that dermatology and skin cancer specialist nurses are used effectively throughout the patient pathway. Peer Review will continue to be important in ensuring that MDTs are utilising the expertise within their teams effectively to provide the appropriate care for patients in their communities.



2015 Vision

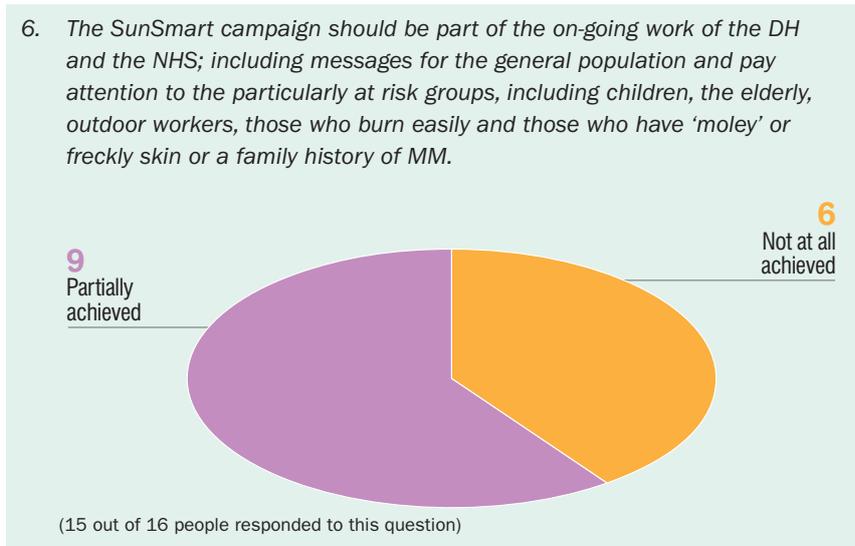
- The criteria for Peer Review should be developed to cover more than just the basic, minimum standards of care and should reflect the holistic issues that are important for each person with a melanoma, including psychosocial care and support.
- Mandating parallel working in clinics of surgeons, specialist nurses, dermatologists, plastic surgeons and oncologists would create cost savings and efficiencies while driving up the quality of care and patient outcomes. This will reduce the number of patient visits and deliver truly multidisciplinary care for patients.
- A strategic review of the nursing workforce in melanoma should be undertaken to ensure that the division of labour between doctors and nurses is clarified so that both can be deployed more effectively. This review should consider the heavy workload that skin cancer nurses are placed under in comparison to other tumour groups.
- The introduction of melanoma Quality Standards in a refreshed IOG on skin tumours including melanoma would provide a robust service framework and outcome goals that will guide the new GP consortia in commissioning skin cancer services and give renewed focus to practitioners and MDTs.
- A refreshed IOG, that includes Quality Standards for patient outcomes, mandates a more flexible approach by MDTs, enabling innovation in service design and the best use of clinical expertise to develop services that meet the needs of patients in the local area.

C. Prevention

Taskforce analysis

Awareness and prevention

6. *The SunSmart campaign should be part of the on-going work of the DH and the NHS; including messages for the general population and pay attention to the particularly at risk groups, including children, the elderly, outdoor workers, those who burn easily and those who have 'moley' or freckly skin or a family history of MM.*



Graph 6 gives the Taskforce's view on the improvements in awareness and prevention of skin cancer since 2007. It shows that despite the continuation of campaigns such as SunSmart, the group feels that messages about the dangers of skin cancer are not being taken on board by the most at-risk groups.



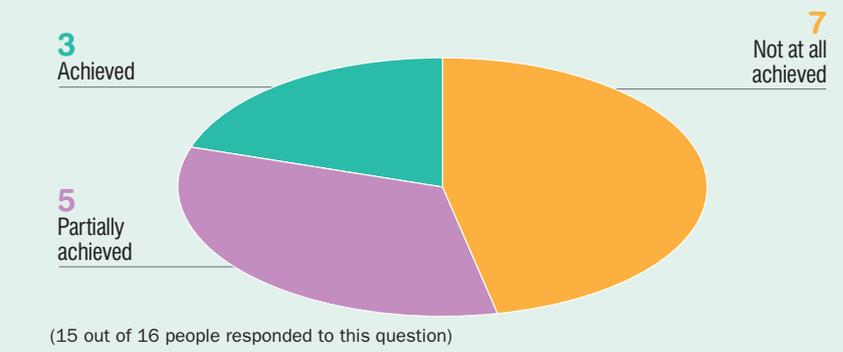
Taskforce findings continued

There was considerable debate amongst Taskforce members about the effectiveness of different approaches to skin cancer prevention taken by organisations in the UK and across the world. In the current financial climate, the Government will not be able to prioritise resources to mobilise mass media campaigns along the Australian model that so successfully embedded the ‘slip slap slop’ mantra into the public consciousness. However, it was the consensus view of the Taskforce that charities need to work together with the Government and the NHS to target messages about the dangers of overexposure to the sun to the most susceptible groups. This needs to be coupled with public information on the signs of skin cancer and the importance of early detection, similar to those the Government is now piloting in breast, lung and bowel cancer.

SKCIN, Cancer Research UK, Teenage Cancer Trust and the British Association of Dermatologists have led a number of innovative and creative skin cancer awareness campaigns. These have focused on raising awareness about the dangers of sun damage; changing attitudes and behaviours related to sun protection and highlighted the signs of skin cancer through successful internet and off line campaigns. The NHS should work with charities, organisations and patient groups to find new ways of communicating messages about prevention and early diagnosis of skin cancer and utilise social media to reach more young people.

The role of public health

9. *NICE should develop public health guidance on prevention and early detection of skin cancer, including its implementation at a local level.*



The NICE guideline on skin cancer prevention will be published in early 2011. The Taskforce hopes that this will provide new impetus for public health directors to put robust prevention strategies in place. This guidance comes at the same time as a number of other key developments that will provide additional opportunities to produce better, more targeted, skin cancer prevention strategies.

For example, the Public Health Consultant at the Lead Cancer Network for skin cancer prevention conducted a survey of PCTs to find out what they are doing to raise awareness about skin cancer prevention. The results of this will provide a useful audit of good practice that can be shared nationally to highlight areas where patient groups and the DH may need to focus their attentions.

Under the Government’s Public Health White Paper, responsibility for public health will shift from the NHS to local government. It is vital that the new management structures give greater priority to skin cancer prevention strategies to bring them



in line with programmes tackling smoking, obesity and alcohol. The evidence linking survival gains and falls in mortality with skin cancer prevention programmes will need to be robust and a strong case put to the Department of Health in the forthcoming consultation as to why skin cancer should be given as equal a weight as other public health concerns.

By making public health a local authority responsibility, the Taskforce hopes that there will be a more holistic approach to skin cancer prevention strategies. There was consensus among members that skin cancer awareness should not be a priority for the NHS alone. Schools, communities and businesses, supported by the Departments for Education, Communities and Business in partnership with local authorities, should take responsibility for educating people about the importance of protecting skin from excessive sun exposure and support the use of protective clothing and shaded public spaces.

Other professionals, for example pharmacists, hairdressers, physiotherapists and swimming instructors should also be educated on how to help people spot the signs of skin cancer to enable them to seek advice from their GP.

CASE STUDY

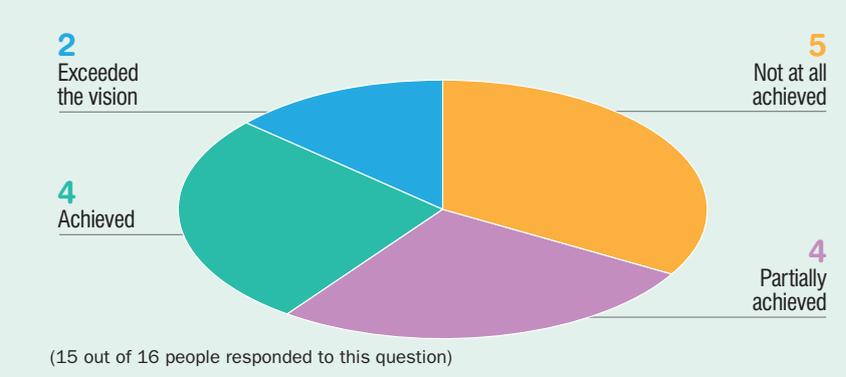
Catherine Wheelhouse,

Clinical Nurse Specialist Skin Cancer, Bradford Teaching Hospitals NHS Trust

“We did a pilot study with children to see if they could bring the same messages home to their parents about the dangers of skin cancer as they have done with lung cancer in anti-smoking campaigns. It actually worked. The parents that came along said they came home and said, ‘You really should not be doing that, sitting out in the garden frazzling’ the way they were. We need to shout about small local programmes that have been successful so other areas can replicate them.”

Sunbed regulation

11. Action should be taken to improve the regulation of sunbeds.



Sunbed regulation was considered by the Taskforce as one of the areas where the most progress had been made out of all the 2012 Skin Cancer Visions. This is clearly due to the ban on sunbed use for under-18s that will be effective from April 2011.



Taskforce findings continued

This is just one of several battles that need to be won if the number of young people experiencing skin damage through the use of sunbeds is going to be reduced significantly. Further action to prohibit coin operated, unsupervised sunbed salons will be necessary if young people are to be further protected from this form of skin damage.

2015 Vision

- Skin Cancer charities need to work collaboratively with public health directors to target messages about the dangers of overexposure to the sun and the importance of early detection to the most susceptible groups. This could be in the form of local pilots as currently being tested in breast, lung and bowel cancer.
- Full implementation of the NICE guideline on skin cancer prevention by local authorities and public bodies.
- Clear and targeted information for professionals that come into contact with people's skin e.g. pharmacists, hairdressers, physiotherapists, swimming instructors, on how to spot the signs of skin cancer and how to advise people on the need for swift GP advice.
- Further regulations on sunbed use to ensure all salons are supervised and that all adult users of sunbeds are provided with health information warnings about the dangers of sunbed exposure.

D. Screening

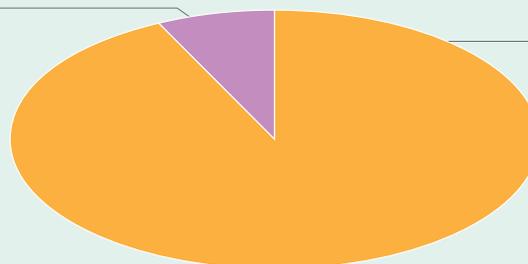
Taskforce analysis

Screening

12. *DH to hold pilots to see if targeted screening in more focused groups could be clinically or cost-effective.*

1
Partially
achieved

13
Not at all
achieved



(14 out of 16 people responded to this question)

The Taskforce felt that screening for skin cancer was the area where least progress had been made since the CRS was introduced (graph 12). However, it was the consensus view of the Taskforce that universal screening would be inefficient and unaffordable. Instead, people should be made aware of the danger signs in a mole that require expert advice through public awareness campaigns and these campaigns should target those that are most at risk from skin cancer.

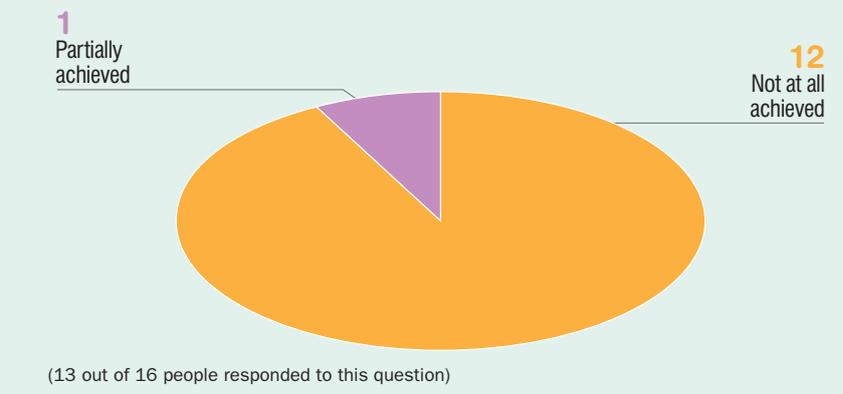
The charitable sector and patient groups have led much of the work in prevention and awareness to date. They could also play an expanded role in



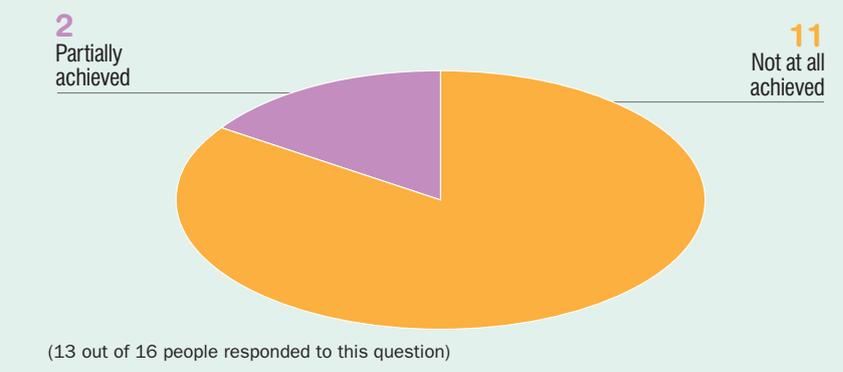
providing services such as mole watch sessions that would provide additional capacity to local health services. However, it should be stressed that screening for melanoma is a very specialised activity and services such as this rely on the goodwill of NHS dermatologists to donate their time which may not be sustainable if this service is to be extended under the current model.

GP Training

13. *DH to establish a tool to help GPs stratify the risk of potential skin cancers.*



14. *More teaching on dermatology both in medical schools and at postgraduate level.*



Graphs and 13 and 14 give a stark analysis of the improvements in GP training and diagnostic resources achieved in the last four years. Half the members of the Taskforce felt that GPs received no more teaching on dermatology now than in 2007. This raises serious questions about the ability of primary care practitioners such as GPs to diagnose potential malignancies and refer patients for further treatment. Often it is not about the GP being able to make a diagnosis there and then, but knowing the danger signs to look for in moles and taking the appropriate course of action.

The group agreed that those assessing pigmented lesions in primary care need better training and education and skin cancer needs to be robustly addressed in the curriculums for all clinical students, including medical, nursing and pharmacist students as well as other healthcare professionals, such as chiropodists.



Taskforce findings continued

CASE STUDY

Dr Jerry Marsden,
President, UK Melanoma Study Group, University Hospitals Birmingham

"We conducted a small survey of skin cancer patients at our centre that found that over 40% had had multiple contact with healthcare professionals prior to diagnosis. This suggests a failure to recognise the basic symptoms and signs."

2015 Vision

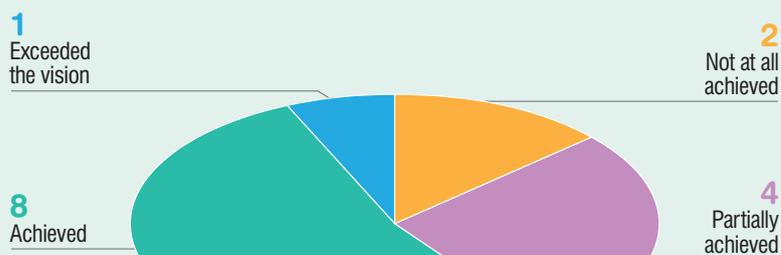
- The Taskforce recommends that GPs should receive more training in dermatology and that mandatory training in how to recognise melanoma should be considered.
- An easy to follow guide for healthcare professionals should be developed by the Department of Health in conjunction with professional and patient group partners on different sorts of lesions. The underlying message should reinforce the 'if in doubt, get it checked out' slogan already used by the British Association of Dermatologists.

E. Diagnosis and staging

Taskforce analysis

Updating guidelines

18. *The British Association of Dermatologists, British Association of Plastic Surgeons and the Melanoma Study Group need to regularly update multidisciplinary guidelines on diagnosing, staging and managing melanoma and other skin cancers.*



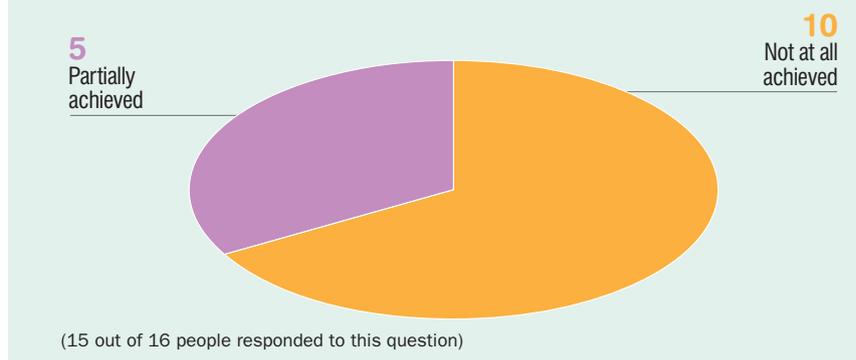
(15 out of 16 people responded to this question)

8 out of the 16 members of the Taskforce that responded to this part of the survey felt that the British Association of Dermatologists, British Association of Plastic Surgeons and the Melanoma Study Group do provide regular updates to the multidisciplinary guidelines on diagnosing, staging and managing melanoma and other skin cancers. However, as other responses to the survey have revealed, these guidelines are not always adhered to by practitioners, particularly those working in primary care as highlighted in the discussion on GP training.



Sentinel node biopsy

17. There should be access to sentinel node biopsy (SNB) across the country and sufficient numbers of surgeons and histopathologists to manage the increased number of procedures.



The practice of sentinel node biopsy (SNB) and its availability and funding in England is a contentious issue which was reflected in the responses to the survey (graph 17) and the debate among members of the Taskforce.

Patient access to SNB varies widely, depending on whether a unit offers the procedure and has surgeons trained to undertake it. There is considerable uncertainty about the effectiveness of SNB as a diagnostic tool and whether it constitutes a cost effective intervention. If effective adjuvant therapies become available, SNB could be used to assess the suitability of patients with intermediate thickness melanoma for these treatments.

There are concerns that centres that don't offer SNB also don't tell patients about the procedure or give them the choice of travelling to other units that do. The Taskforce agreed that it would not be practicable to have SNB provided in all units, but it is important that patients have equality of access and can exercise patient choice.

2015 Vision

- Better training and guidance for GPs and primary care professionals on dermatology and the signs of skin cancers will improve patient outcomes and enable them to become more involved in the implementation of the IOG at that level.
- National standards, perhaps NICE guidance, on the use of Sentinel Node Biopsy (SNB), based on robust evidence of its usefulness as a staging tool, would provide much needed equity for patients and clarity to clinicians and commissioners about its role in the patient pathway.



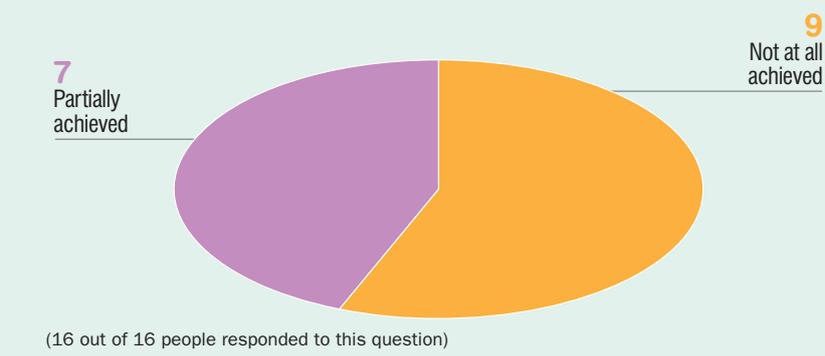
Taskforce findings continued

F. Treatment

Taskforce analysis

Treatment

23. Equal access to new treatments.



Much of the focus in skin cancer and melanoma policy is, rightly, about prevention and awareness of the disease to stop people from developing malignancies in the first place. However, the group was clear that there must be equally robust strategies in place for those who do develop malignant disease, especially as this is a condition that disproportionately affects younger people.

The survey found that none of the Taskforce members felt the Vision for equal treatment access had been achieved (graph 23). Members of the group agreed that it is crucial that the UK does not get left behind comparable European countries in melanoma survival and so access to new treatments and procedures is vital. Patients should have equal access to clinical trials and if some trials are not available in their Trust, patients should have full information about the nearest centre running the trial to give them the choice of travelling to take part.

Metastatic melanoma is notoriously difficult to treat and until recently, there have not been any breakthroughs that significantly increased patient survival. By 2015, there will be new systemic therapies available which will need to be routinely accessible for use in the NHS if the treatment of melanoma is not to be left behind other tumour types. Adjuvant studies may demonstrate the benefits of new therapies for people at earlier stages of the disease, as has been the case with other tumours, so further clinical trials will be important to establish what additional improvements in patient outcomes can be achieved.

The new treatments which are currently emerging are targeted therapies which will necessitate mutation testing of tumours for predictive biomarkers. Additional histopathology and diagnostic resources will therefore need to be built into the treatment pathway.



CASE STUDY

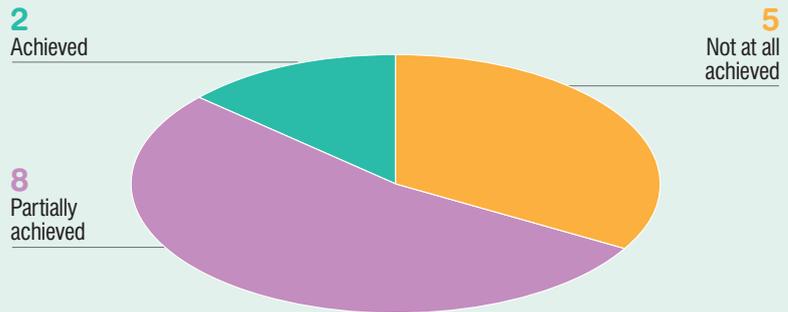
Dr James Larkin,

Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust

“Equity of access to clinical trials is a real issue. There are lots of patients, particularly those with advanced disease, who do not necessarily have that access. We have patients referred from a very wide geographical area, sometimes coming up from Cornwall and from further afield. Now, not everyone wants to come from Cornwall to London to go into a clinical trial if they have advanced melanoma. However, I think that an opportunity to discuss that with a clinician is an important option for everybody with melanoma.”

Vitamin D

24. NCRI research proposals should consider the effect of Vitamin D on relapsed melanoma, and to identify predictors of relapse and response to treatment, should have progressed.



(15 out of 16 people responded to this question)

There is continuing debate over the potential benefits to patients of Vitamin D, the recommended quantities people should receive and its most appropriate source. During her campaign to introduce regulations on sunbed use, Siân James MP faced fierce opposition from those who attest to the benefits of Vitamin D and she expressed her concern that there is a lot of misleading and contradictory information being provided to people under the guise of medical advice.

Clear advice to people on how to balance skin cancer prevention advice with the need to make enough Vitamin D, and which reflects the latest scientific evidence, is urgently needed. However, the arguments are complex and the evidence base is incomplete. A consensus statement on Vitamin D will shortly be available which represents the unified views of the British Association of Dermatologists, Cancer Research UK, Diabetes UK, the National Heart Forum, the National Osteoporosis Society and the Primary Care Dermatology Society.

2015 Vision

- The Taskforce recommends that patients should have equitable access to new treatments as they become available in the NHS to ensure that UK melanoma survival rates do not fall behind other comparable countries or tumour types. Patients should also have equitable access to information on all open clinical trials for new treatments in development and be given the choice to take part in them.
- As further evidence about the recommended levels of Vitamin D becomes available, clear advice to patients as to how to balance their Vitamin D intake while avoiding sunburn should be urgently developed.



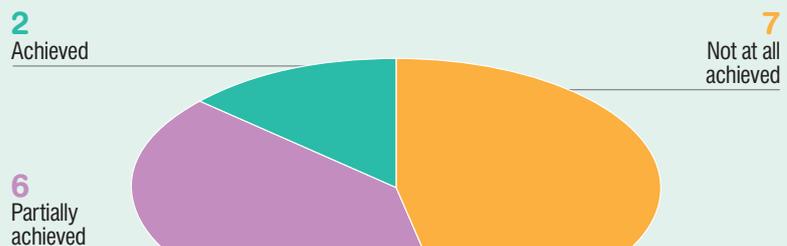
Taskforce findings continued

G. Supportive and palliative care

Taskforce analysis

Patient support

29. *Better provision of information to patients in a variety of formats and languages about skin cancer and skin cancer services.*



(15 out of 16 people responded to this question)

The Taskforce expressed consistently the need for patients to have greater involvement and choice in their treatment and care. This should include the instatement of patient representatives on Cancer Surveillance Groups (CSGs), patient surveys to get feedback on the quality of services and relevant and timely information to patients throughout the treatment pathway.

The NHS White Paper calls for an information revolution in the NHS so patients can access information about services and care and then make choices about how and where they are treated. The Taskforce was keen that patients should have clear information about the best possible pathway for them, with guidance on how to ensure they receive best practice care. By doing so, more of the hidden inequity of patchy service provision will be highlighted and evidence provided so that the problem can be tackled.

National Patient Information Pathways for Melanoma and Non-Melanoma Skin Cancers already exist as a useful resource in primary care. However, Cancer Networks need to inform MDTs and PCTs about local implementation. Likewise, Patient Information Prescriptions are beginning to be used in skin cancer but this needs to happen more widely and CNSs need to be given the resources and the time to make them useful to patients.



CASE STUDY

Dr Dafydd Roberts,

Consultant Dermatologist, ABM University NHS Trust

“We have just done a national survey in Wales of patient experience with skin cancer. It is a qualitative questionnaire and we all found that very useful because we had unexpected results back. We all thought we were doing perfectly and while most patients are happy, some surprising issues came up. If we could agree a national questionnaire for use in all services it would be very useful for making comparisons on the quality of patient experiences. We plan to do this at least every two years to see how our service is developing.”

CASE STUDY

Dr Paul Lorigan,

Consultant Medical Oncologist, Christie Hospital NHS Trust

“In our survey of melanoma patients, we found that 40% of them had anxiety and/or depression but that 20% of those had not made it aware to the clinical team. There are a lot of co-morbidities in skin cancer that are not being dealt with at present.”

2015 Vision

- Patient information needs to clearly set out the following for patients: their entitlements; what the best practice patient pathway should look like; and how to seek redress if they do not get it.
- Cancer Networks need to inform MDTs and PCTs about local implementation of National Patient Information Pathways for Melanoma and Non-Melanoma Skin Cancers.
- The use of Patient Information Prescriptions and targeted, relevant information sources needs to be rolled out more widely and CNSs need to be given the resources and the time to make them useful to patients.



Conclusions: 2015 Skin Cancer Visions

The recommendations of the Taskforce represent the group's Vision for skin cancer services in 2015. These are goals that should not just be the aspirations of the refreshed CRS, but those of public health directors that will be responsible for implementing NICE's guideline on skin cancer prevention in 2011.

The Taskforce feels that these recommendations are not only achievable over the next five years but are necessary to change attitudes and behaviours towards sun protection and halt rising incidence and mortality rates from skin cancer in England. Siân James MP and members of the Taskforce will continue to work with the Department of Health to ensure that the new CRS includes measures to improve patient outcomes in melanoma. We also look forward to working with NCAT to share the learnings from supporting Cancer Networks to prioritise skin cancer prevention, providing public health leadership and aligning local and national action.

Recommendations

- 1) The NCIN should work with practitioners throughout the patient pathway to ensure universal compliance on measuring, recording and reporting to the skin cancer registry by clinicians across England. Compliance with data collection should be monitored via Peer Review.
- 2) The NCIN should undertake a review of the Skin Cancer Hub to ensure that it provides useful and relevant information to the new directors of public health leading on skin cancer awareness and prevention strategies in local authorities.
- 3) The criteria for Peer Review should be developed to cover more than just the basic, minimum standards of care and should reflect the holistic issues that are important for each person with a melanoma, including psychosocial care and support.
- 4) Mandating parallel working in clinics of surgeons, specialist nurses, dermatologists, plastic surgeons and oncologists would create cost savings and efficiencies while driving up the quality of care and patient outcomes. This will reduce the number of patient visits and deliver truly multidisciplinary care for patients.
- 5) A strategic review of the nursing workforce in melanoma should be undertaken to ensure that division of labour between doctors and nurses is clarified so that both can be deployed more effectively. This review should consider the heavy workload that skin cancer nurses are placed under in comparison to other tumour groups.
- 6) The introduction of melanoma Quality Standards in a refreshed IOG on skin tumours including melanoma would provide a robust service framework and outcome goals that will guide the new GP consortia in commissioning skin cancer services and give renewed focus to practitioners and MDTs.
- 7) A refreshed IOG, that includes Quality Standards for patient outcomes, mandates a more flexible approach by MDTs, enabling innovation in service design and the best use of clinical expertise to develop services that meet the needs of patients in the local area.
- 8) Skin Cancer charities need to work collaboratively with public health directors to target messages about the dangers of overexposure to the sun and the importance of early detection to the most susceptible groups. This could be in the form of local pilots as currently being tested in breast, lung and bowel cancer.



- 9) Full implementation of the NICE guideline on skin cancer prevention by local authorities and public bodies.
- 10) Clear and targeted information for professionals that come into contact with people's skin, including pharmacists, hairdressers, physiotherapists and swimming instructors, on how to spot the signs of skin cancer and how to advise people on the need for swift GP advice.
- 11) Further regulations on sunbed use to ensure all salons are supervised and that all adult users of sunbeds are provided with health information warnings about the dangers of sunbed exposure.
- 12) The Taskforce recommends that GPs should receive more training in dermatology and that mandatory training on how to recognise melanoma should be considered.
- 13) An easy to follow guide for healthcare professionals should be developed by the Department of Health in conjunction with professional and patient group partners on different sorts of lesions. The underlying message would reinforce the 'if in doubt, get it checked out' slogan already used by the British Association of Dermatologists.
- 14) Better training and guidance for GPs and primary care professionals on dermatology and the signs of skin cancers will improve patient outcomes and enable them to become more involved in the implementation of the IOG at that level.
- 15) National standards, perhaps NICE guidance, on the use of Sentinel Node Biopsy (SNB), based on robust evidence of its usefulness as a staging tool, would provide much needed equity for patients and clarity to clinicians and commissioners about its role in the patient pathway.
- 16) The Taskforce recommends that patients should have equitable access to new treatments as they become available in the NHS to ensure that UK melanoma survival rates do not fall behind other comparable countries or tumour types. Patients should also have equitable access to information on all open clinical trials for new treatments in development and be given the choice to take part in them.
- 17) As further evidence about the recommended levels of Vitamin D becomes available, clear advice to patients as to how to balance their Vitamin D intake while avoiding sunburn should be urgently developed.
- 18) Patient information needs to clearly set out the following for patients: their entitlements; what the best practice patient pathway should look like; and how to seek redress if they do not get it.
- 19) Cancer Networks need to inform MDTs and PCTs about local implementation of National Patient Information Pathways for Melanoma and Non-Melanoma Skin Cancers.
- 20) The use of Patient Information Prescriptions and targeted, relevant information sources needs to be rolled out more widely and CNSs need to be given the resources and the time to make them useful to patients.



Glossary

Adjuvant therapies

Adjuvant treatment is given in addition to the primary (initial) treatment. Adjuvant therapy for cancer usually refers to surgery followed by chemo- or radiotherapy to help decrease the risk of the cancer recurring.

Biomarkers

A biomarker is a substance used as an indicator of a biological state. It is a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention.

Cancer Networks

Cancer Networks were formed in response to national policy to drive change and improve cancer services for the population in specific areas. Healthcare professionals, patients and carers work collaboratively to plan and deliver high quality cancer services within a given area. Networks base much of their work around the patient pathway, which is the route patients take through the healthcare system from first contact with the NHS through referral, diagnoses and completion of their treatment.

Cancer Surveillance Group (CSG)

Cancer Surveillance Groups (CSG) were set up to meet a perceived need for a forum bringing together those with an interest in the use of cancer data. They have tended to have loose, open and informal memberships and structure. Members typically include epidemiologists and statisticians, as well as other registry staff.

Clinical Nurse Specialists (CNSs)

Clinical Nurse Specialists (CNSs) are clinical experts in the diagnosis and treatment of a particular illness. Cancer CNSs play a role across many different elements of cancer patient management and support, carrying out a range of technical, informational, emotional and coordination functions, working within Multi-disciplinary teams (MDTs).

Cancer Reform Strategy (CRS)

First published in 2007, and under the direction of National Clinical Director for Cancer, Professor Sir Mike Richards, the CRS is designed to provide a comprehensive direction for cancer policy, outlining support to commissioners and providers on how to deliver high quality and cost-effective cancer services. The CRS sets out a programme of action across ten areas, including prevention, early diagnosis, reducing inequalities and ensuring better treatment. The Coalition Government announced a review of the CRS in the July 2010 in order to ensure that it is aligned with its revised priorities for the NHS.

Improving Outcomes Guidance (IOG)

The IOG is a series produced by NICE and the National Collaborating Centre for Cancer, to provide advice to those who develop and deliver cancer services on the planning, commissioning and configuration of those services. The IOG referred to in this document is the 2006 IOG to Improve Healthcare Services for Skin Cancers. An updated version of this guidance was published in May 2010.

Lesion

A lesion is any abnormal tissue found on or in an organism, usually damaged by disease or trauma.

Malignant melanoma

Malignant melanoma is a cancer of the melanocytes which are found between the two layers of the skin, the epidermis and the dermis. More than 10,000 people are diagnosed with malignant melanoma every year.

Multidisciplinary Teams (MDTs)

A Multidisciplinary Team (MDT) is a team of specialists in a given disease area and NHS network. The MDT meets regularly to plan aspects of patient treatment. Individual patient cases might be discussed at an MDT meeting so that the best approach to treatments can be decided and planned.



National Cancer Action Team

The National Cancer Action Team (NCAT) is a national team that reports to the National Cancer Director. Its role is to support the NHS and facilitate the implementation of the Cancer Reform Strategy. It works closely alongside the Cancer Policy Team in the Department of Health and with the SHAs and cancer networks.

National Cancer Intelligence Network (NCIN)

The National Cancer Intelligence Network (NCIN) was launched in June 2008 to bring together cancer registries, clinical champions, health service researchers and a range of other interested parties under the auspices of the National Cancer Research Institute. It supports the collection, analysis and publication of high quality data on clinical outcomes which are key drivers for the implementation of the Cancer Reform Strategy.

National Patient Information Pathways

The National Cancer Action Team (NCAT) is working with charity partners to develop National Cancer Information Pathways, offering high quality information to the increasing numbers of people who have survived, or continue to live with, cancer.

NHS White Paper

The NHS White Paper, 'Equity and Excellence: Liberating the NHS', sets out the Coalition Government's long-term vision for the future of the NHS. It is intended to strengthen patient choice and engagement, create a service focussed on the outcomes it delivers to patients and empower clinicians to innovate to improve healthcare services. The Government is currently consulting on the proposals and will take forward its proposals in 2011.

NICE

The National Institute of Health and Clinical Excellence (NICE) is a special health authority of the NHS in England and Wales. It provides guidance, sets quality standards and manages a national database to improve people's health and prevent ill health. It sets national guidance to ensure that everyone has equal access to cost-effective medical treatments and high quality care from the NHS – regardless of where they live in England and Wales.

NICE Guidance on the Prevention of Skin Cancer

NICE's draft guidance on 'Skin cancer: how the NHS and local authorities can help prevent skin cancer using public information, sun protection resources and by making changes to the environment' was published in August 2010. A consultation on the proposals was recently completed and the final guidance will be published early in 2011.

National Cancer Peer Review (NCPR)

National Cancer Peer Review (NCPR) is a national quality assurance programme for NHS cancer services. The programme involves both self-assessment by cancer service teams and external reviews of teams conducted by professional peers, against nationally agreed "quality measures". NCPR is managed by the National Cancer Action Team and is an integral part of the NHS Cancer Reform Strategy (2007) and the overall NHS Cancer Programme, led by the National Cancer Director.

Patient Information Prescriptions

Information prescriptions can be offered to anyone with a long-term condition or social care need, in consultation with a health or social care professional. They guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence. Information prescriptions can be used as a source of key information on conditions, services and care that is seamlessly and formally integrated into the care process. They provide a way for organisations to meet patients' rights to information to support choice and to enable people to be involved in discussions and decisions about their care, as set out in the NHS Constitution.



Glossary continued

Patient Related Experience Measures (PREMs)

PREMs measure each person's experience of their pathway and highlight what have been good or bad experiences of the care, treatment and support they have encountered. Collation of these measures will support commissioners and providers to continue good parts of the pathway and reconsider bad parts that need changing. PREMs allow patients to provide measurable qualitative information that can influence service provision. PREMs do not replace any formal complaints procedures.

Patient Reported Outcome Measures (PROMs)

PROMs measure quality from the patient perspective. PROMs calculate the health gain after surgical treatment using pre and post operative surveys. PROMs are measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time. The health status information collected from patients by way of PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to NHS Patients.

Quality Standards

NICE quality standards are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence such as NICE guidance and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with the NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience. This work is central to supporting the Government's vision for an NHS focussed on delivering the best possible outcomes for patients.

Sentinel Node Biopsy (SNB)

Sentinel node biopsy (SNB) is a surgical procedure that doctors use to stage (determine the extent of spread of) certain types of cancer in patients who have been recently diagnosed with cancer. Sentinel node biopsy is most commonly associated with staging breast cancer; but the procedure is also commonly used to stage malignant melanoma.

Skin Cancer

Skin cancer is one of the most common cancers in the UK and the number of people who develop it is increasing. Most skin cancers are caused by too much ultraviolet (UV) radiation – the kind found in sunlight and sunbeds. There are two main types of skin cancer: malignant melanoma (see above); and non-melanoma skin cancer (NMSC). Malignant melanoma is the most serious type of skin cancer. NMSC is more common and easily treated. There are two main types of NMSC: basal cell cancer and squamous cell cancer. These cancers are most common on areas of skin frequently exposed to the sun such as the head, neck, hands and forearms.

Skin Cancer Visions

As part of the development of the Cancer Reform Strategy, groups of experts including clinicians and patient representatives were brought together to produce visions for a range of cancers and cancer-related services. The groups considered the whole patient pathway from prevention to supportive and palliative care along with issues that underpin services such as workforce and information. The outcome is a series of vision documents summarising what the groups thought would change over the next five years and their aspirations for what services should be like by 2012. The Melanoma Taskforce looked at the progress made towards implementing the Skin Cancer 2012 Visions and this report makes recommendations for 2015 Visions in skin cancer prevention and treatment.

SunSmart

SunSmart is a national skin cancer prevention campaign, providing evidence-based information about skin cancer and sun protection. The campaign is commissioned by the UK Health Departments and run by Cancer Research UK.

2015 Skin Cancer Visions

 The Melanoma Taskforce

Supported by

