



# The Melanoma Taskforce

Chaired by Siân James MP

## Quality in Melanoma Care:

A best practice pathway





# About the Melanoma Taskforce

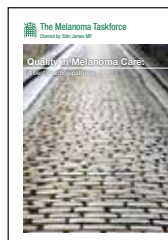
The Melanoma Taskforce is a panel of skin cancer experts, chaired by Siân James MP, comprising of patient group and charity representatives (including Cancer Research UK, The Teenage Cancer Trust, Skcin and Factor50) GPs, skin cancer nurses, dermatologists, oncologists and surgeons, as well as representatives from the National Cancer Action Team and the National Cancer Intelligence Network. The cost of administration of the group is supported by Bristol-Myers Squibb, who have no editorial control over any recommendations made by the Taskforce.



The Taskforce was set up by Siân James MP in 2010 in order to make practical recommendations as to how the prevention and treatment of skin cancer, and particularly melanoma, could be improved. In October 2010, the Taskforce published a report, '2015 Skin Cancer Visions' setting out its recommendations for how skin cancer and melanoma services and treatment could be improved over the life of the new Department of Health (DH) cancer strategy, 'Improving Outcomes: A Strategy for Cancer' published in January 2011. As part of the new strategy, the DH published its own '2015 Skin Cancer Visions', which adopted 17 of the 20 recommendations made by the Melanoma Taskforce.



In June 2011, the Taskforce worked in partnership with the British Association of Dermatologists (BAD) and a coalition of well-being, hair and beauty professional associations to develop 'Mole and Skin Check Guidelines', an information leaflet providing clear and simple information about the signs of skin cancer for people working in the health and beauty industry who regularly come into contact with people's skin. The Taskforce is currently working with the Hair and Industry Authority (Habia) to take this project forward and embed skin cancer awareness in the standard training of relevant non-health professionals.



Having concentrated in 2011 on the prevention and early diagnosis of skin cancer, the Taskforce decided to turn its attention to treatment and the quality of melanoma care. In November 2011, the Taskforce published its *Variations in Melanoma Survey*, which examined variations in the standard of care for melanoma patients in England, and led to the establishment of the Expert Working Group, whose findings are set out in this report.

For more information about the Melanoma Taskforce, please contact the Taskforce Secretariat on 020 7824 1850.

The Taskforce includes representatives from the following groups:



The cost of administrative support for this project has been provided by Bristol-Myers Squibb, who have no editorial control over the Taskforce recommendations.



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## Professor Sir Mike Richards

National Cancer Director



“The Government has set a stretching ambition to improve cancer survival rates by saving an additional 5,000 lives per year by 2014/15. This cannot be achieved by focussing on the common cancers alone, and so I am very pleased to welcome this Taskforce report which makes recommendations which could help improve melanoma survival rates.

We all recognise the importance of preventing melanoma and diagnosing it early, to have the best possible chance of treating it successfully. But, as the report highlights, there are variations in outcomes which are likely to relate to variations in treatment. The Taskforce’s focus on what good treatment looks like provides a very valuable contribution to supporting services to deliver the best possible treatment.

While much of the focus is on improving cancer mortality rates, improvements to services will also help in relation to other outcomes being prioritised by the Government, particularly patient experience of care.”

Professor Sir Mike Richards CBE  
National Cancer Director



# Siân James MP

Chair, Melanoma Taskforce



I am delighted to introduce *Quality in Melanoma Care: a best practice pathway* which marks the latest authoritative publication of the Melanoma Taskforce. When I set up the Taskforce two years ago, I wanted to bring the leading clinical and patient experts in the country together into a forum that could present consensus and practical recommendations as to how skin cancer -and particularly melanoma - care could be improved. I am proud of the work we have achieved to date, and once again it has been extremely satisfying for me to see an esteemed group of experts working together in pursuit of high quality melanoma care for all. I am immensely grateful to the group's Chair, Dr James Larkin, for his excellent work in guiding this project to fruition.

I commissioned the *Quality in Melanoma Care* project at the end of last year after the Taskforce's own research suggested that the extent of variation in the treatment and management of melanoma across the NHS required further investigation. We know that the Government has already taken steps to prioritise the treatment of melanoma in the NHS, and the Taskforce was delighted to receive notification of NICE's decision to develop a Quality Standard for Skin Cancer (including melanoma). This is a vital step in improving melanoma care and I hope that the Expert Group's set of 16 quality statements, and 21 supporting recommendations, will prove to be a valuable resource for NICE and the NHS Commissioning Board as both the Quality Standard and accompanying commissioning guidance are developed.

I think that this project demonstrates the difference and important contribution that the Melanoma Taskforce is able to make in raising the standard of melanoma care for all. With the continuing support of Bristol Myers-Squibb, for which we are very grateful, I look forward to working alongside my Taskforce colleagues as we strive to see our recommendations and quality statements implemented in the NHS.

Siân James MP, Chair Melanoma Taskforce



## Dr James Larkin

Chair, Melanoma Pathway Expert Group  
Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust



When Sian James MP first invited me to act as Chair of an Expert Group of melanoma specialists in a project to critically assess the melanoma care pathway, I was honoured and delighted to accept. As a practising clinician for the last 15 years and a Consultant Medical Oncologist for the last five, I have a longstanding interest in the advancement of melanoma research and I saw this as a unique opportunity to work together with colleagues from across the pathway to look at how we can improve the quality of care for melanoma patients.

As a Consultant at the Royal Marsden, I am fortunate to work in a centre of excellence in cancer care and research but one of the most pleasing aspects of this project is that it has drawn on the experience and excellence of other centres across the UK. For this reason, the *Quality in Melanoma Care* project has been a particularly unique undertaking, with some of the country's leading names in melanoma, including GPs, nurses, surgeons, oncologists and patient groups, represented to address each part of the pathway.

I am pleased that as a multi-disciplinary group we have been able to agree on the key principles of high quality melanoma care, but the road to consensus has not been straightforward. It is always a challenge when experts with international reputations come together with differing, and at times conflicting, viewpoints. The strength of this project is that we have not avoided the difficult issues but arrived instead at a consensus view through rigorous and informed debate. That is why as a group we believe that this report represents an important critique of the melanoma pathway, and we hope that specialist cancer networks, the Department of Health and the National Cancer Action Team will take heed of our recommendations and work with us to put them into practice.

Dr James Larkin, Chair, Melanoma Pathway Expert Group



# Chapter 1

## Introduction

### Overview

#### Scope

The Expert Group has limited itself to examining the cutaneous melanoma pathway since the various types of cutaneous melanoma make up around 90% of all diagnosed malignant melanomas. Therefore, where 'melanoma' is used in the text, the group is referring to cutaneous melanoma.

#### Objectives

Siân James MP approved the establishment of a multi-disciplinary Expert Group in order to:

- Look critically at existing melanoma treatment pathways;
- Identify areas of best practice care and performance to ensure that these are not lost during a period of organisational flux within the NHS;
- Propose a series of statements that describe high quality care in melanoma;
- Recommend improvements to the melanoma treatment pathway in order to reduce variation in the quality of clinical care and improve patient outcomes;
- Inform and support commissioners so that melanoma patients have access to the right quality care, at the right time, irrespective of location.

*Quality in Melanoma Care: a best practice pathway* is a critical assessment of the melanoma pathway and the quality of care that patients receive from beginning to end: from first presentation right the way through to survivorship or end of life care. The Expert Group's report outlines a series of standards that describe high quality care in melanoma to which all providers can aspire. These standards draw on an analysis of existing national guidance, current clinical practice, and the application of the members' own clinical and professional perspectives.

The report has been produced by the Melanoma Pathway Expert Group, set up by Siân James MP and chaired by Dr James Larkin, Consultant Medical Oncologist at the Royal Marsden NHS Foundation Trust. The group is made up of 16 eminent members drawn from a breadth of clinical settings and patient groups.

The *Quality in Melanoma Care* project was commissioned in the autumn of 2011 after the results of a Melanoma Taskforce survey demonstrated the extent of variation in the treatment and management of melanoma across the NHS in England. Critically, data on incidence and mortality across England presented by the SWPHO suggested that the variation might not solely be explained by environmental factors and variation in incidence. Melanoma incidence has risen sharply in recent decades, a trend which is set to continue. This will increase the pressure placed on melanoma services to meet the rising demand at the same time as attempting to improve patient outcomes.

The Government is rightly focussing its efforts on prevention and early diagnosis of cancer but treatment and the quality of care also need to be addressed if melanoma outcomes are to be improved. To achieve this it is vital that commissioners and cancer networks are given the necessary support and guidance to redesign their services accordingly. Results from the Taskforce survey showed that half of cancer networks and almost the same proportion of Acute Trusts suggested that Commissioning Support and Guidance would enable them to improve melanoma care and 30 per cent of Acute Trusts, and 31 per cent of Cancer Networks, said that a comprehensive and standard clinical pathway would also help improve care for patients with melanoma.<sup>1</sup>

Siân James MP and the Melanoma Taskforce recognised this direction of travel, and the Government's focus on improving quality through a focus on outcomes, and felt that now is the time to address problems in the melanoma pathway, to reduce variation and improve the quality of care patients receive. The Taskforce put together the expert group of clinicians and patient representatives not simply to define the problems, but also to identify solutions.

<sup>1</sup> Melanoma Taskforce Freedom of Information Request (2011)



## Professional membership

The multi-disciplinary Expert Group is made up of professionals from across the melanoma pathway including: nurses; surgeons; GPs; dermatologists; oncologists; and patient representatives. A great deal of excellent work is being done in melanoma, including by the National Cancer Intelligence Network (NCIN), the National Cancer Research Institute (NCRI) and multiple patient groups including Cancer Research UK, Skcin and Factor50. The Expert Group is in a strong position to contribute to this existing body of work and to address the entire continuum of melanoma care from first presentation and diagnosis through to end of life care, proposing recommendations for its improvement.

## Development process

The Expert Group met on two separate occasions (7 February 2012 and 1 May 2012) and worked virtually during the intervening time for a total of five months, from February to June 2012.

At the first meeting in February, the Expert Group split into five core teams: primary care; dermatology; surgery; oncology; and survivorship and end of life. Each of the five core teams focused on one part of the pathway. A cross-cutting group was also established with the remit to review the work of all five core teams and ensure that the proposed recommendations were aspirational, achievable, measurable and focused on improving patient outcomes. The feedback from the cross-cutting group was considered by each of the five core teams and incorporated where appropriate.

At the second meeting in May, the group as a whole reviewed the provisional recommendations from each of the five core teams and distilled these down to a set of 16 'quality statements' and a series of additional recommendations. The Expert Group focused on developing a set of quality statements that described the level of care melanoma patients should expect in the NHS. These statements have been produced with a view to presenting a standard of care that is aspirational, but achievable. This is in line with the definition of Quality Standards from NICE that describes them as "specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions." Indeed, the Taskforce took a conscious decision throughout to align the process by which these quality statements have been produced with NICE's own procedures. This has included the forming of an Expert Group in the image of the Topic Expert Groups utilised by NICE and by following NICE's own evidence gathering and consultation processes as far as possible within the timelines set for this project.





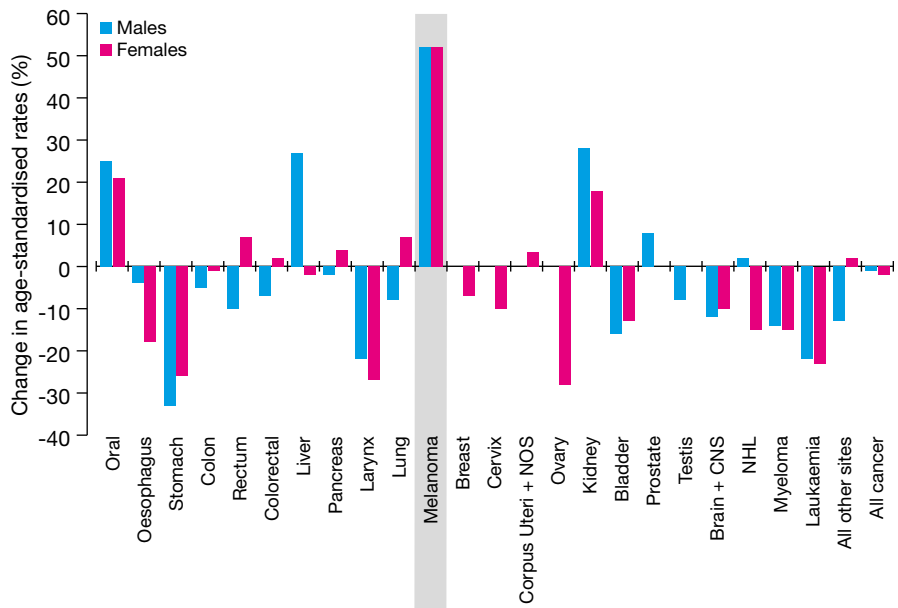
# Melanoma care in England

## Incidence & Mortality

Melanoma incidence has risen sharply in recent decades. In 2011, Cancer Research UK reported that over the last 25 years, rates of melanoma in Britain had risen faster than any of the top ten cancers in both men and women and this trend shows no signs of abating.<sup>2</sup> Rates of incidence in melanoma are forecast to rise by over 50% by 2030, which is the biggest projected increase of any form of cancer.<sup>3</sup> This rapid rise in incidence is in part due to the fact that people who have historic sun damage from excessive sun exposure are at an increased risk of developing melanoma and could therefore develop the cancer in spite of potentially improved sun safety habits. In light of this, melanoma is predicted to become the fourth most common male cancer by 2030, having been ranked only 14<sup>th</sup> in 1984.<sup>4</sup>

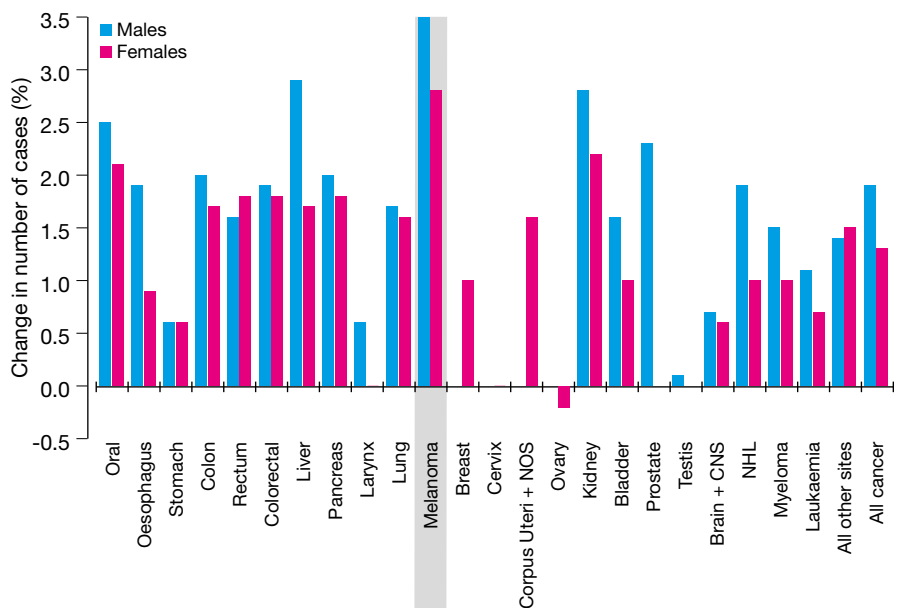
### Change in age-standardised rates of specific cancers in men and women in 2007 and 2030.

Data sourced from British Journal of Cancer, Cancer incidence in the United Kingdom: projections to the year 2030 (2011) p. 3



### Change in number of cases of specific cancers in men and women in 2007 and 2030.

Data sourced from British Journal of Cancer, Cancer incidence in the United Kingdom: projections to the year 2030 (2011) p. 3



<sup>2</sup> Cancer Research UK, CancerStats Key Facts: skin cancer (2012)

<sup>3</sup> British Journal of Cancer, Cancer incidence in the United Kingdom: projections to the year 2030 (2011) p.3

<sup>4</sup> British Journal of Cancer, Cancer incidence in the United Kingdom: projections to the year 2030 (2011)



Although not the most common type of skin cancer, melanoma causes the most deaths.<sup>5</sup> Studies suggest that more years of life and lifetime earnings are lost on average to melanoma than compared to most other forms of cancer.<sup>6</sup> In the last 30 years, death rates in the over-65s have almost tripled. Like most cancers, skin cancer is more common with increasing age, but according to data from Cancer Research UK, melanoma is disproportionately high in young people. More than two young adults (aged 15 – 34) are diagnosed with melanoma every day in the UK and it is the second most common cancer in this age group.<sup>7</sup>

Early detection is critical in melanoma. Survival rates are significantly better for people diagnosed early with the thinnest tumours. However, if the tumour is not detected early it can be very difficult to treat. In 2010, 2,203 people died from malignant melanoma in the UK; in 2008 the mortality figure for melanoma was an estimated 46,000 worldwide.<sup>8</sup>

## Variation

In 2010, the National Cancer Equality Initiative published *Reducing Cancer Inequality: evidence, progress and making it happen*. This report highlighted the range of inequalities in the outcomes and experience of cancer patients, occurring at every stage of the pathway. This included variation in public awareness, incidence rates, access to treatment and care, patient experience, survival and mortality. Variation in patient access to high quality care also appears to be influenced by socio-economic factors including deprivation, ethnicity, age, disability, religion, gender and sexual orientation.<sup>9</sup>

Critically, data (overleaf), supplied by the South West Public Health Observatory (SWPHO) demonstrates that the geographical variation in the rates of melanoma incidence and mortality across England could not solely be explained by environmental factors and variation in incidence. Dr Veronique Poirier, Principal Cancer Intelligence Analyst at the SWPHO, told the Melanoma Taskforce that variation in the rate of melanoma incidence could be attributed to the composition of the population, socio-economic distribution and sun and UV light exposure and indeed that variation in mortality could of course then be impacted by varying incidence. However, Dr Poirier noted that the level of public awareness, late presentation and the variation in the quality of care provision and delivery could also be responsible.

There is evidence of variation in the quality of care delivered right across the NHS; it is not isolated to one single area of care. When addressing the NHS Alliance Conference in 2011, Secretary for State for Health, Rt. Hon. Andrew Lansley MP, acknowledged this fact and said that it was plain that “the degree of variation is considerable and unexplained by simple differences in population.” In order to address this variation in cancer care, the Government’s Cancer Strategy aims to not only save an additional 5,000 lives every year by 2014/2015 but to tackle this range of inequalities in the outcomes and experience of cancer patients.

5 According to statistics from Cancer Research UK, in 2010 2,203 people died from malignant melanoma compared to 546 from non-melanoma skin cancer. <http://info.cancerresearchuk.org/cancerstats/types/skin/> (2011) p3

6 Journal of Clinical Oncology, Impact of mortality due to malignant melanoma versus other cancers, (2008), 26: (May 20 suppl; abstr 20016) [http://www.asco.org/ascov2/Meetings/Abstracts?&vmview=abst\\_detail\\_view&confID=55&abstractID=35944](http://www.asco.org/ascov2/Meetings/Abstracts?&vmview=abst_detail_view&confID=55&abstractID=35944)

7 Cancer Research UK, CancerStats Key Facts: Skin cancer (2012)

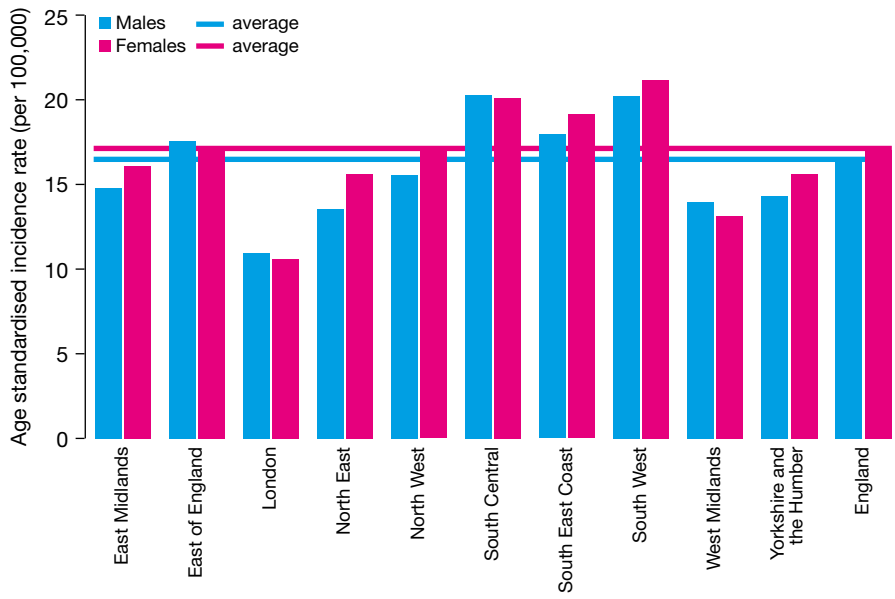
8 Cancer Research UK, CancerStats Key Facts: Skin cancer (2012)

9 National Cancer Equality Initiative: Department of Health, Reducing Cancer Inequality: evidence, progress and making it happen (2010) p.3



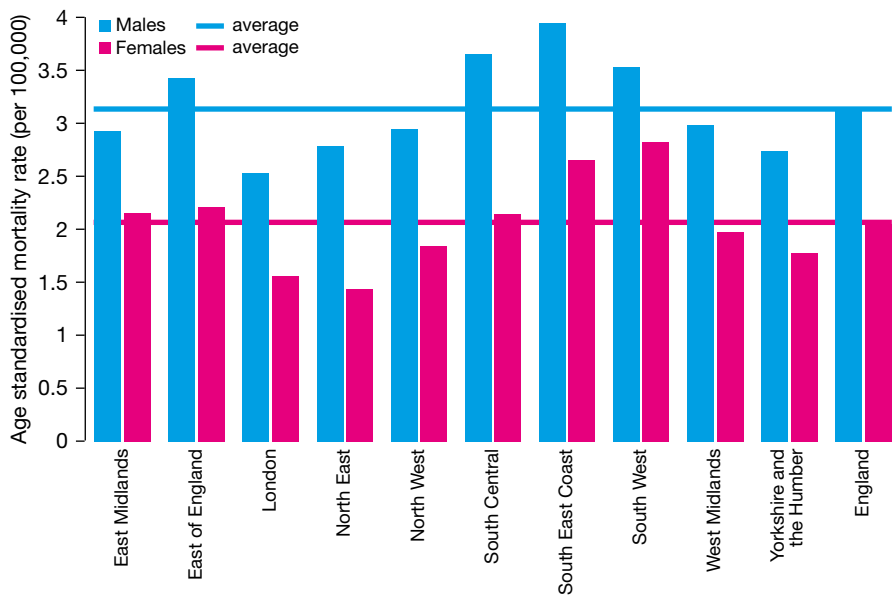
**Age-standardised incidence rate for malignant melanoma in England 2007-09**

*National Cancer Data Repository and Office of National Statistics*



**Age-standardised mortality rate for malignant melanoma in England 2008-10**

*National Cancer Data Repository and Office of National Statistics*





## Evidence Sources

Foreword

Introduction

Quality Statements  
& Pathway Map

Primary Care

Dermatology

Surgery

Oncology

Survivorship  
& End of Life

Service Design  
& Implementation

Glossary

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- NICE Guidance, *Patient Experience in adult NHS Services* <http://guidance.nice.org.uk/index.jsp?action=byId&o=13259> (2011)
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- The Melanoma Taskforce, Freedom of Information request, Available on request from the Melanoma Taskforce Secretariat (2011)





# Melanoma Pathway Expert Group: Membership



**Dr James Larkin FRCP PhD (Chair)**  
*Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust*

James Larkin is a Consultant Medical Oncologist at The Royal Marsden Hospital, London, specialising in the treatment of renal cancer and melanoma. He was appointed to his current post in 2008, and his research interests include the individualisation of patient treatment in renal cancer and melanoma, the identification of mechanisms of sensitivity and resistance to systemic therapies, intratumour heterogeneity and the use of novel therapies in combination to treat these diseases.

Dr Larkin is UK Chief Investigator for a number of clinical trials in melanoma and kidney cancer, and has been awarded research grants from bodies including Cancer Research UK, The Wellcome Trust and the European Union Framework Programme 7.



**Simon Davies**  
*Chief Executive, Teenage Cancer Trust; Chairman, Cancer52*

Simon Davies has been Chief Executive of Teenage Cancer Trust since 2000. He has successfully focused on developing Teenage Cancer Trust's specialist health facilities for teenagers and young adults with cancer throughout the UK. It has become a nationally recognised force for change within the NHS, thereby advancing the status of cancer medicine for young people. Teenage Cancer Trust is responsible for the acclaimed Shunburn Campaign, educating young people about sun safety.

Simon is also Chairman of Cancer 52. 52 per cent of UK cancer deaths are from the less common cancers (recent statistics show an increase to 53 per cent). Despite this, the less common cancers remain severely under-represented and under-funded across all areas, including policy, services and research. Cancer52 is an alliance of over 50 organisations working to address this inequality and improve outcomes for patients with these highly challenging diseases.



**Charlotte Fionda**  
*Development Director, Skcin (The Karen Clifford Skin Cancer Charity)*

Charlotte Fionda is Development Director for The Karen Clifford Skin Cancer Charity (Skcin) and Skin Cancer UK. Charlotte works to raise awareness of the dangers of over exposure to UV from the sun and or sunbeds, educating on sun safety via awareness campaigns and promoting the early detection of skin

cancers, whilst offering patient information, support and campaigning for access to treatments and care.



**Dr Stephen Kownacki**  
*Executive Chair, Primary Care Dermatology Society*

Dr Kownacki developed an interest in dermatology on the Northampton VTS scheme under the guidance of Dr Dick Coles, founder of the Psoriasis Association. He worked as a hospital practitioner at Northampton General Hospital for almost 30 years. He retired in July 2011 from being senior partner in a large Wellingborough practice which is active in developing Practice based commissioning services as well as many aspects of medical research and teaching at all levels.

He remains active in the education of registrars locally, particularly on the dissemination of knowledge and the development of learning practices. Dr Kownacki is involved with all aspects of PCDS activities especially the Essential Dermatology series and the new Dermoscopy for Beginners courses which he chairs and at which he lectures. He represents the society on many stakeholder groups, the Dermatology Council for England (DCE) and the All Party Parliamentary Group on Skin (APPGS).



**Dr Paul Lorigan**  
*Senior Lecturer in Medical Oncology, University of Manchester; Honorary Consultant Medical Oncologist, Christie NHS Foundation Trust*

Paul Lorigan's main clinical research interest is in malignant melanoma. He chaired the UK NCRI Melanoma Clinical Studies Group from 2006 to 2012, and is a member of the EORTC Melanoma CSG and a number of other research groups. He is principal investigator on a number of clinical trials. In addition to clinical trials, the Manchester Melanoma Group has a broad research portfolio in basic and translational research. This includes signalling pathways, biomarkers in circulating tumour cells, immunotherapy and adoptive cell therapy, and pre-clinical melanoma models. He leads the clinical team that works closely with these groups. This close cooperation has seen significant increase in research output and clinical trial accrual over the last 3-5 years.

Dr Lorigan has been involved in a number of other initiatives including the Melanoma Taskforce, as an advisor to Factor 50, and a Trustee of the Melanoma Focus Charity. He acts in an advisory capacity to many national and international groups.



**Dr Jerry Marsden**  
*Consultant Dermatologist, University Hospital Birmingham NHS Foundation Trust; Chair, Melanoma Study Group*

Dr Marsden's main interest is therapeutics of melanoma, in particular surgery, regional chemotherapy, and adjuvant treatment of stage II and III disease. He is Chair of the

UK Melanoma Study Group (MSG), a board member of the European Association of Dermato-Oncology (EADO) and a member of the National Cancer Research Institute (NCRI) Melanoma Clinical Studies Group; he is Principle Investigator and Chief Investigator on a number of UK and European melanoma trials.



**Professor Julia Newton-Bishop**  
*Chair, Skin Site Specific Clinical Reference Group, National Cancer Intelligence Network; Professor of Dermatology, Leeds University Hospital*

Julia Newton-Bishop is Professor of Dermatology at the University of Leeds. She leads the melanoma research group within

the Section of Epidemiology and Biostatistics in the Leeds Institute of Molecular Medicine. Julia is Chair of the National Cancer Intelligence Network's (NCIN) Skin Site Specific Clinical Reference Group (SSCRG) and is a member of the Melanoma Study Group (MSG).



**Gill Nuttall**  
*Founder, Factor50*

Gillian Nuttall is the founder of Factor 50, a patient support group formed in 2008. Factor 50's remit is to support patients and families who are suffering due to malignant melanoma and also provide fund raising and support to various doctors and consultants. Factor 50 became part of the

Melanoma Taskforce in 2010.



**Dr Veronique Poirier**  
*Principal Cancer Intelligence Analyst, South West Public Health Observatory*

Veronique Poirier graduated in Paris undertaking her postgraduate qualification at the Institute Curie. After 15 years as a scientist working in the field of cancer research, she joined the South West Public

Health Observatory (SWPHO) as a Senior Cancer and Public Health Information Analyst. The SWPHO is the lead cancer registry for Skin Cancer in England. It provides intelligence support for the National Cancer Intelligence Network Skin Cancer Site Specific Reference Group and responds to requests from the Department of Health, clinicians, researchers and members of the public. SWPHO has provided expert guidance to many public bodies including NICE, COMARE and SunSmart.



**Professor Barry Powell**  
*Consultant Plastic Surgeon, St George's Healthcare NHS Trust*

Professor Powell is a Professor in Plastic and Reconstructive Surgery, London; National Clinical Adviser in Skin Cancer; Chair, Skin Cancer Section, London Cancer Alliance (LCA); Chair, SW Thames Skin Cancer Tumour Working Group; and Head of Melanoma Services, St. George's Hospital, South London.

Professor Powell graduated from Trinity College, Dublin, in 1978. He completed his early training in Dublin and then moved to England to embark on a Plastic Surgery career. Professor Powell started in Queen Mary's Hospital, Roehampton, and then carried out the senior part of his training in Frenchay Hospital, Bristol and The Royal Marsden Hospital, London.

He spent two years researching possible treatment strategies for malignant melanoma at the Institute of Cancer Research, Sutton and was awarded the Higher Degree of Master in Surgery (MCh) for this work. Further to this, Professor Powell introduced the concept of Sentinel Node Biopsy for malignant melanoma into the UK. In 1994 he was appointed Consultant to St. George's Hospital, Tooting and Queen Mary's Hospital, Roehampton.



**Saskia Reeken**  
*Cancer Nurse Specialist Skin Cancer and Dermatology, Kingston Hospital NHS Trust; Skin Cancer Group Chair, British Dermatological Nursing Group*

Saskia has worked for many years in Dermatology and Skin Cancer, gaining extensive experience initially as an

Outpatients sister and later CNS. After some years as Macmillan CNS Skin Cancer at St George's Hospital, Saskia moved to Kingston Hospital NHS Trust, setting up and facilitating services for skin cancer and dermatology patients.

She is currently the chair of the British Dermatological Nursing Group's (BDNG) Skin Cancer sub group and board member of the British Association of Skin Cancer Nurses (BASCN) and actively works with other groups such as BAD Skin Cancer Committee, Skin Cancer UK, Melanoma Taskforce and the SunSmart Advisory Board, to take national skin cancer issues and education forward.



**Dr Dafydd Roberts**  
*Consultant Dermatologist, Swansea NHS Trust*

Dr Dafydd Roberts is a Consultant Dermatologist in Swansea. He has published several papers on various aspects of skin cancer including being the lead author for the first published UK guidelines on melanoma. He was the Lead Clinician for

the NICE 'Improving Outcomes guidance for skin cancer, including Melanoma' and subsequently Clinical Lead for Skin Cancer for the DH (England).



**Dr Neil Shroff**  
*Accredited GPwSI Skin Cancer;  
Committee Member, Primary Care  
Dermatology Society*

Neil qualified at Charing Cross and Westminster Medical School in 1995. He did basic surgical training at the Norfolk and Norwich Hospital obtaining the Associate Fellowship of the Royal College of Surgeons

of Edinburgh in 1999. He held hospital posts in Plastic Surgery and completed the Nottingham vocational training scheme in 2005. During this time he completed the Diploma in Clinical Dermatology based at St Barts and the London Hospital in 2006.

In 2007 Neil, along with one of his partners, developed a community skin cancer service that served a population of 110,000 and would see between 12-15 new patients a week. In 2009 the service won a national practice-based commissioning award for 'best dermatology redesign'. Neil has given talks to newly qualified GPs and Primary Care Nurses, additionally he has taught dermatological surgery on national courses training dermatology nurses. He is the GP representative for the East Midlands Skin Cancer Network and has been an active participant in skin cancer audit.



**Professor J Meirion Thomas**  
*Consultant Surgeon and Professor in  
Surgical Oncology at Royal Marsden  
Hospital and Imperial College,  
London*

Professor Meirion Thomas is a Consultant Surgeon at the Royal Marsden Hospital and heads Surgery on the Sarcoma and Melanoma Unit. In the last calendar year,

almost 500 new sarcomas were referred for diagnosis and treatment. The melanoma work is equally busy with about 250 new patients each year.

Professor Thomas has a large publication record including two articles in the New England Journal of Medicine. Currently, he heads the SUNMEL study. This is a prospective trial to test the efficacy of ultrasound screening and surveillance of regional lymph nodes in melanoma as an alternative to sentinel lymph node biopsy.



**Jacky Turner**  
*Lead Oncology Pharmacist, Guy's &  
St Thomas' NHS Foundation Trust*

Jacky Turner has been the Lead Oncology pharmacist at Guys and St Thomas' and Network Pharmacist for South East London Cancer Network for the last 6 years. She has many years of experience in oncology and completed her Masters in Clinical

Oncology in 1996. She is a member of the London Cancer New Drugs Group and has worked with the SELCN network team and Network Pharmacists in London to lead on the prioritisation of cancer medicines in London and latterly in developing a process for the implementation of the Cancer Drugs Fund in London.



**Catherine Wheelhouse**  
*Skin Cancer Clinical Nurse  
Specialist, Bradford Teaching  
Hospital NHS Trust; Chair, British  
Association of Skin Cancer Specialist  
Nurses*

Catherine is the Lead Clinical Nurse Specialist for Skin Cancer at Bradford Teaching Hospitals Foundation NHS Trust.

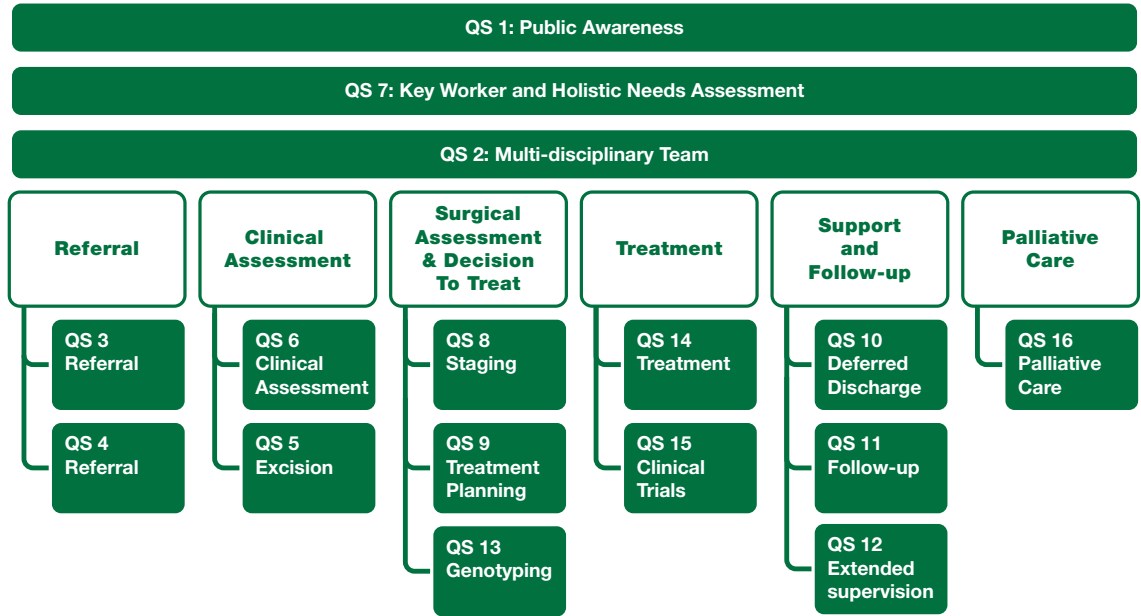
She is a core member of the Bradford Skin Cancer MDT and is the lead for Service Improvement and User Involvement. Catherine is also the lead for Service Improvement and User Involvement and Information for the Yorkshire Cancer Network and is Chair of the British Association of Skin Cancer Nurse Specialists.

She produces and leads the inauguration of the Clinical Examination and Case Management (skin cancer) Masters Module at the University of Bradford and lectures at the University of Bradford regarding prevention and the holistic care of skin cancer patients. In 1995 Catherine was awarded the Royal College of Nursing Cancer Nurse of the Year Award for her work for skin cancer nursing.



# Treatment of Cutaneous Melanoma: The Melanoma Care Pathway

The following map shows how the Quality Statements, detailed below, correspond with the appropriate section of the melanoma care pathway.



## Quality Statements

- 1 People are made aware of the symptoms and signs of melanoma through national and local co-ordinated public awareness campaigns.
- 2 People with melanoma should have access to a multi-disciplinary team comprising all specialist core members with clinics running simultaneously to facilitate timely clinical discussion and decision making.
- 3 Patients newly diagnosed with stage 2B or higher melanoma (or stage  $\geq 1B$  if SLNB is offered) should be referred to a SSMDT in line with current national guidance.
- 4 People with a suspected melanoma, when being referred by a GP are done so within the Urgent Suspected Cancer (USC) framework (Two Week Wait), and where possible a photograph of the suspected lesion should be taken, in order to aid triage.
- 5 People with a suspected melanoma should have the lesion excised completely, as incisional, punch biopsy, or curettage of melanoma may prejudice the measurement of Breslow thickness and may also lead to incorrect histopathological diagnosis as a result of sampling error.





- 6 People with suspicious lesion(s) have a full history of the lesion(s) taken, followed by a detailed examination of the findings, including: a differential clinical diagnosis; a clinical photograph; and histopathology. All information gathered in the process of diagnosis is available to an LSMDT or to a SSMDT to minimise the risk of error in agreeing upon the final diagnosis.
- 7 People with melanoma have access to a named “key worker” who will normally be a SCCNS, (but may be an alternative named member of the Skin Cancer MDT), and are offered a holistic needs assessment, including psychological support requirements, at each key stage of care.
- 8 Although sentinel lymph node biopsy (SLNB) has no established survival value, it is a staging tool for melanoma. People with primary melanoma should be given a clear description of this procedure, its risks and benefits and information on appropriate clinical trials. Those who choose to have a SLNB should be referred promptly to the centre of their choice.
- 9 People having treatment for melanoma are offered timely and personalised information and support including an appropriately-tailored written follow up care plan.
- 10 Melanoma patients with good prognosis melanoma (AJCC stage 0 to 1A), who have had a second Out-Patient Department (OPD) appointment and SCCNS consultation following definitive surgery, may be offered Deferred Discharge (discharge allowing subsequent rapid access back to their Skin Cancer Service if they display symptoms that are cause for concern).
- 11 Patients (AJCC stage 1B to IV) will have regular specialist follow up, 3 monthly for 3 years, thereafter 6 monthly for 2 years, which can include protocol-led clinical nurse specialist follow-up. After the 5 year period of specialist follow-up, Deferred Discharge is discussed with the patient.
- 12 Melanoma patients with a family history of melanoma or atypical naevus syndrome will require longer term supervision by specialist services which have access to photography using dermoscopy.
- 13 People with  $\geq$  Stage IIIB melanoma should be offered genotyping of their melanoma to allow subsequent planning of systemic treatment by the multidisciplinary team.
- 14 Patients with advanced cutaneous melanoma should have equitable access to the full range of available clinically-appropriate therapeutic options.
- 15 People with melanoma, including Teenagers and Young Adults (16 -24), are offered the opportunity to take part in NCRN approved clinical trials for which they are eligible within the NHS, irrespective of where the trial is taking place. Teams should demonstrate contribution to NCRN trials in the preceding 3 years.
- 16 Patients with melanoma have access to all appropriate palliative interventions delivered by an expert nominated clinical team.



# Treatment of Cutaneous Melanoma: Expert Group Recommendations

- 1 Skin Cancer charities should work collaboratively with public health directors to target messages about the dangers of overexposure to the sun and the importance of early detection. Cancer Networks should disseminate the clear and targeted information that is being made available to professionals who have access to people's skin, including beauty therapists, barbers and hairdressers.
- 2 All GPs should have access to training in the diagnosis, triage and referral of patients with suspected melanoma. This training should be made available to undergraduate and postgraduate medical students and be part of GP training and continuous professional development. The group would suggest that the Royal College of General Practitioners (RGCP) is best placed to take this recommendation forward.
- 3 Changes are made to the medical curriculum to ensure that students are aware of characteristics in the patient's medical history that suggest skin cancer and can recognise common benign lesions on examination. Students should also be made aware of the dermoscope and its uses.
- 4 GPs should be sufficiently incentivised to train as GPwSIs in order to build a workforce with the necessary expertise in skin cancer. This could include financial incentives and a place on the local MDT.
- 5 Patients with brain metastases should have access to the full range of therapeutic options including stereotactic radio-surgery.
- 6 Applying the Enhanced Recovery Programme to melanoma could improve patient outcomes and experience and the cost effectiveness of care. Settings where melanoma patients are identified as elective rather than emergency patients, would be best placed to lead on the implementation of the ERP in melanoma.
- 7 Closer working between the Local Hospital Skin Cancer Multi-Disciplinary Team (LSMDT) and the Specialist Skin Cancer Multi-Disciplinary Team (SSMDT) will ensure the safe, equitable and co-ordinated delivery of services with the patient at its centre.
- 8 Research should be carried out to ascertain trends in the age of patients with melanoma who receive a major resection. This would contribute to our understanding of the likelihood of patients over 50 years old opting for surgical interventions (i.e. the age group where the burden of disease is heaviest).
- 9 Further research should be carried out on how data should be collected on where trials are offered and where participation is secured. This research should also look at how the data should be published and audited.
- 10 Patients with advanced melanoma should have equitable access to all approved treatments, where clinically appropriate, in order to provide those patients with the best possible chance of long-term survival.



**11** At each follow-up appointment, whether it is with a dermatologist, plastic surgeon or CNS the patient's surgical scar, skin and lymph nodes should be examined. The patient will be asked to undress down to their underwear, removing their shoes and stockings to enable all of the patient's skin to be examined at each visit.

**12** In line with the National Cancer Action Team's Manual for Cancer Services<sup>1</sup>:  
*"At least one clinical core member of the team should have completed the training necessary to enable them to practice at level 2 for the psychological support of cancer patients and carers."* (11-2J-103)  
*"The level 2 practitioner should receive a minimum of 1 hour's clinical supervision by a level 3 or level 4 practitioner per month."* (11-2J-104)  
 SSMDTs should offer patients, their family members, partners and significant carers psychological support services in line with the service delivery of other cancer sites. This should be in line with the NICE 2004 guidance on Improving Supportive and Palliative Care Adult Cancer.

1 National Cancer Action Team (NCAT) (2011), National Cancer Peer Review Programme: Manual for Cancer Services, Version 2.0

**13** Patients should have access to the SCCNS from the Breaking Bad News Consultation (BBNC) onwards. Following the BBNC, the patient should be: given time with SCCNS to further discuss their treatment options and plans; given relevant information in accordance with the treatment plan; directed to further information that they can access in their own time; given contact numbers; allocated a Key Worker; and be given a holistic assessment by the SCCNS or Key Worker.

**14** All MDTs should have a defined referral pathway to a nominated clinical team for patients requiring palliative care input.

**15** Appropriate data collection systems should be put in place to collate, publish and audit post-surgery morbidity and complication rates.

**16** Standardised coding in data collection should be put in place to allow for accurate comparisons to be made between networks at both the local and national level.

**17** The provision of melanoma care must be delivered via an integrated system, irrespective of the provider. Private and public sector providers must be able to communicate effectively and ensure that decisions on the patient's care pathway are made with all of the necessary members of the clinical team involved.

**18** Clinical Commissioning Groups should manage the workforce capacity in accordance with the increasing demand for specialist skin cancer services to ensure that patients within their commissioning area have equitable access to high quality melanoma care.

**19** The NHS Commissioning Board should develop commissioning guidance for the provision of melanoma services to secure equitable access to high quality, specialised, melanoma care across the country.

**20** The group recommends the swift publication of the NICE Quality Standard for Skin Cancer (including melanoma) and that NICE guidance Improving outcomes for people with skin tumours (including melanoma) (2006/2010) is updated in accordance with the newly published Quality Standard.

**21** The NHS Commissioning Board should consider the level of specialism within the strategic clinical cancer networks, as well as the value of establishing a melanoma lead at the local level in order to provide the necessary leadership and guidance in the development of this complex pathway.



## Chapter 2 Primary Care

### Group Membership

Charlotte Fionda	Development Director, Skcin (The Karen Clifford Skin Cancer Charity)
Dr Stephen Kownacki	Executive Chair, Primary Care Dermatology Society
Dr Neil Shroff	Accredited GPwSI Skin Cancer; Committee Member, Primary Care Dermatology Society

### Introduction

Although not the most common type of skin cancer, melanoma causes the most deaths.<sup>1</sup> More than two young adults (15-34) are diagnosed with melanoma every day in the UK (over 900 cases were diagnosed in this age-group in 2008)<sup>2</sup> and the total number of people diagnosed each year is forecast to exceed 20,000 by 2030.<sup>3</sup> Unless it is detected early, melanoma is also harder to treat and so primary care professionals are best placed to drive up rates of early diagnosis in the NHS. The Expert Group was unanimous in its belief that in order to manage the increasing demand for melanoma services, it is vital that the NHS invest in capacity and expertise in primary care. This was particularly pertinent when discussing the role of GPs with a Special Interest (GPwSIs), and although there was much debate around specialisation in primary care, it was clear that the Expert Group considered professional education for GPs as central to combating poor diagnosis in melanoma.

### Discussion

#### Public Awareness

The Melanoma Taskforce's report, *2015 Skin Cancer Visions*, made it clear that public awareness of the risks, signs and symptoms of melanoma should be improved. The report recommended that skin cancer charities work collaboratively with public health directors to target messages to at-risk groups about the dangers of exposure to the sun and the importance of early detection. The Taskforce also recommended that clear and targeted information be made available for professionals who 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. Since the publication of this report in 2011, some progress has been made in advancing these recommendations. However, the Expert Group agreed that there is still much more that could be done.

1 According to statistics from Cancer Research UK, in 2010 2,203 people died from malignant melanoma compared to 546 from non-melanoma skin cancer. <http://info.cancerresearchuk.org/cancerstats/types/skin/> (2011)

2 According to statistics from Cancer Research UK, between 2006-2008, 949 young people aged 15-34 years old were diagnosed with malignant melanoma <http://info.cancerresearchuk.org/cancerstats/types/skin/incidence/#Malignant> (2011)

3 Mistry, M. et al., Cancer Incidence in the United Kingdom: projections to the year 2030, *British Journal of Cancer* (2011), p.3 In terms of the numbers of people diagnosed with the melanoma, the BJC forecast a 118% rise in incidence in men and a 91% rise in women.





## Melanoma Taskforce and British Association of Dermatologists

*Mole and Skin Check Guidelines: Information on the Signs of Skin Cancer for Well-being, Hair and Beauty Professionals*



 The Melanoma Taskforce

In 2011, the Melanoma Taskforce partnered with the British Association of Dermatologists (BAD) to take forward a key recommendation of the '2015 Skin Cancer Visions' report to provide targeted information for non-health professionals, such as hairdressers and beauty therapists, to help them spot the signs of skin cancer in their clients. With the support of nine endorsing organisations, guidelines were produced providing clear and simple advice on skin cancer and how to advise people on the need to seek swift GP advice. Thousands of leaflets containing the guidance have been distributed to salons up and down the country and the Melanoma Taskforce decided earlier this year to take this work forward with the Hair and Beauty Industry Authority (habia) by producing education materials for non-health educators to embed skin cancer awareness across the health and beauty sectors ([www.bad.org.uk/desktopDefault.aspx?TabId=1459](http://www.bad.org.uk/desktopDefault.aspx?TabId=1459)).



## Karen Clifford Skin Cancer Charity (Skcin) Education Programme



The Karen Clifford Skin Cancer Charity (Skcin) firmly believes that in order to combat the soaring rates of skin cancer, education is key. The seeds of sun safety need to be planted in the classroom where sun safe messages should be reinforced as part of a school's duty of care to ensure the health and well being of its pupils. Currently it is not mandatory for schools to have a sun safe policy in place, or to teach sun safety within the national curriculum. Sun Safe Schools has been created and introduced by Skcin to proactively combat this problem. It provides primary schools with an accreditation, in the form of a Sun Safe Schools Award, for implementing sun safe policy and teaching. The scheme provides all the necessary resources for a school to achieve their award at [www.sunsafeschools.co.uk](http://www.sunsafeschools.co.uk)

Teenagers and Young Adults (TYAs) were identified as an important target for prevention and self-examination education. Sunburn in early life is associated with an increased risk of melanoma and TYAs are potentially at greater risk due to lack of awareness of sun safety. It was agreed that information about self-examination should be made available in schools and via youth media channels.



### Quality Statement

People are made aware of the symptoms and signs of melanoma through national and local co-ordinated public awareness campaigns.

### Expert Group Recommendation 1

**Skin Cancer charities should work collaboratively with public health directors to target messages about the dangers of overexposure to the sun and the importance of early detection. Cancer Networks should disseminate the clear and targeted information that is being made available to professionals who have access to people's skin, including beauty therapists, barbers and hairdressers.**

## Professional Education

The Expert Group was unanimous in its view that GPs should have access to comprehensive professional training in order to improve the diagnosis, triage and referral of melanoma in primary care.

*"PCDS members tell us that there is a wide variation in the degree of educational support given to GPs in this respect. They cite reasons such as lack of time, space and funding." Dr Neil Shroff, Committee Member, Primary Care Dermatology Society (PCDS)*

According to NICE *Referral guidelines for suspected cancer*, if a GP has a patient presenting with a lesion suspected to be melanoma, that patient must be seen within the national target for urgent referrals, which is currently set at two weeks.<sup>4</sup> Research from the National Cancer Intelligence Network (NCIN) shows that almost 40 per cent of melanoma patients are referred via the Urgent Suspected Cancer framework (Two Week Wait).<sup>5</sup> Diagnosis for skin cancer following an emergency presentation was just three per cent, lower than any other tumour type.<sup>6</sup> However, it was suggested that the speed at which patients with suspected cancer are being referred by their GP varies to a considerable degree across the country, and whilst

<sup>4</sup> NICE (2005) CG27: Referral guidelines for suspected cancer

<sup>5</sup> National Cancer Intelligence Network, Routes to Diagnosis: NCIN Data Briefing (2010)

<sup>6</sup> National Cancer Intelligence Network, Routes to Diagnosis: NCIN Data Briefing (2010)



people with suspected melanoma are being referred to specialist care through the correct channels, concerns were raised that opportunities for rapid onward referral are potentially being missed. The National Cancer Patient Experience Survey revealed that in some areas up to 17 per cent of patients had seen their GP more than twice before being referred on with suspected cancer, thereby highlighting the number of missed opportunities in primary care for rapid onward referral.<sup>7</sup>

The Expert Group agreed that the present levels of diagnostic skills and skin lesion recognition in primary care are inadequate at least in part as a result of a lack of training in dermatology at undergraduate and postgraduate levels. Skin cancer training should therefore be available to GPs throughout their professional development, from undergraduate training through to qualification and beyond.

Members of the group were concerned that medical students are currently only expected to complete one to two week's training in dermatology. In light of the rising incidence of skin cancer in the UK, the group feels this must be addressed in order to build a workforce suitably equipped to meet the increasing demand for skin cancer services. Once they have qualified, junior doctors should then have the opportunity to develop their knowledge of skin cancer and melanoma further.

### GP Speciality Training Scheme, Leeds Primary Care Trust

As part of the Leeds GP Speciality Training Scheme, trainees



complete a six month outpatient dermatology module, in conjunction with their GP training. Two six month placements are made available to four trainees with the department over the course of a year. The trainees spend half of their time in GP surgeries and half of their time is spent doing outpatient dermatology. The aim of this was to offer the trainees experience in managing common dermatological conditions, which constitute a sizeable proportion of GP attendances, as well as being able to assess which conditions could be managed in general practice and which should be seen in secondary care.

*Michael Sweeting, Training Programme Director, Leeds Primary Care Trust*

### BAD/CRUK GP Skin Cancer Toolkit

In July 2012, Cancer Research UK and the British Association of Dermatologists (BAD) announced the launch of an online educational campaign to help GPs identify red flag skin cancer signs and symptoms. The project, which is funded by the Department of Health and run by Doctors.net.uk, follows a recommendation made by the Melanoma Taskforce '2015 Skin Cancer Visions' report that 'an easy to follow guide for healthcare professionals should be developed...on different sorts of lesions.' The project will run for four months providing a practical toolkit that illustrates the key clinical signs that warrant prompt referral to skin cancer services under the two-week wait rule. Other elements of the joint campaign include a skin lesion recognition resource that enables GPs to browse images and descriptions of different types of cancerous, pre-cancerous and associated lesions, and to view referral guidelines. There is also an accredited educational quiz for GPs to test their knowledge and compare it against their peers, as well as a range of patient case studies and links to other key sources of information.



The Expert Group agreed that continual professional development in the arena of skin cancer and melanoma should actively be encouraged and made more readily available to GPs once they have qualified. Under existing guidance, multi-disciplinary teams (MDTs) are required to host education days for GPs. However, concerns were raised amongst members of the Expert Group that this guidance is not currently being adhered to. These education days not only develop the expertise of GPs and improve their ability to spot and refer patients with suspected melanoma effectively, they also provide a forum for GPs to foster good working relationships with their secondary care colleagues. As valuable as education days are, they tend only to reach those GPs who have an existing and active interest in dermatology and skin cancer. The group agreed therefore that measures should be taken to ensure that all GPs, irrespective of their professional interests, have access to the appropriate standardised training.



### Expert Group Recommendation 2

All GPs should have access to training in the diagnosis, triage and referral of patients with suspected melanoma. This training should be made available to undergraduate and postgraduate medical students and be part of GP training and continuous professional development. The group would suggest that the Royal College of General Practitioners (RCGP) is best placed to take this recommendation forward.

### Expert Group Recommendation 3

Changes are made to the medical curriculum to ensure that students are aware of characteristics in the patient's medical history that suggest skin cancer and can recognise common benign lesions on examination. Students should also be made aware of the dermoscope and its uses.

Concerns were raised amongst members of the group that with the introduction of 'Any Qualified Provider' as part of the Government's reforms to the NHS, professional development and education will be sidelined and not considered a priority when Service Level Agreements are put in place. The Expert Group agreed that the professional development of GPs must be an integral part of the process when commissioning primary care skin cancer services and included in any Service Level Agreements.

## Specialist care

GPwSIs are critical in the drive to improve the early diagnosis and effective referral of patients with suspected melanoma. The nature of the role that GPwSIs can and should play in skin cancer was rigorously debated by the Expert Group. NICE *Improving Outcomes for People with Skin Tumours including Melanoma* (2006)<sup>8</sup> and the British Association of Dermatologists' *Revised guidelines for the management of cutaneous melanoma* (2010)<sup>9</sup> state that lesions suspected to be melanoma should not be excised in primary care, but referred to the Local Skin Cancer Multi-Disciplinary Team (LSMDT) or Specialist Skin Cancer Multi-Disciplinary Team (SSMDT). This is widely understood to be a point of contention and members of the group discussed at length the value of extending the role and remit of GPwSIs in melanoma. It was felt by some members of the group that, in light of the fact that GPwSIs have undergone specific training for their sub-speciality, they are well-placed to excise suspicious pigmented lesions and provide an alternative to the two-week referral route to dermatology. Proponents of this argument suggested that in the context of rising incidence rates in melanoma, coupled with a small dermatology workforce in the UK, GPwSIs could provide the additional specialist capacity required.

Whilst it was widely accepted by members of the group that GPwSIs and GPs have an important role to play in the early diagnosis of melanoma, concerns were voiced as to the uniformity and reliability of expertise in primary care. On this basis, members of the group felt that excisions should still take place in secondary care under the governance of the MDT where surgery can be planned to allow for subsequent wide local excision with better scars.

8 NICE, *Improving Outcomes for People with Skin Tumours including Melanoma* (2006)

9 British Association of Dermatologists, *Revised UK guidelines for the management of cutaneous melanoma* (2010)



It was understood by all members of the group that the medical workforce is experiencing some significant shifts due to changing trends in specialisation. In its submission to the Expert Group, the Primary Care Core Team highlighted the fact that the skill set of GPs is varied across the country; there are potentially too few sufficiently qualified dermatologists and plastic surgeons in skin cancer; and medical professionals are increasingly looking to work part-time thereby limiting specialisation further.

As skin cancer services face increased demand it will be important to consider how more GPs can be encouraged to specialise in the field. To ensure a standardised level of service delivery, all GPwSIs must go through the formal accreditation process, in accordance with NICE's *Improving Outcomes Guidance for People with Skin Tumours including Melanoma* and *Guidance and competences for the provision of services using GPs with Special Interests (GPwSIs): Dermatology and skin surgery*.<sup>10</sup> As the NHS moves towards more integrated service delivery, GPwSIs will be well placed to act as an interface between primary care and secondary care. The Expert Group agreed that closer working between GPwSIs and local and specialist MDTs will be crucial in facilitating the delivery of integrated care in skin cancer.

*“There are several examples of skin cancer community clinics nationally which have been shown to work. One that stands out is the Kent and Canterbury model. This has a cohort of skin surgery GPswSIs. These individuals are permitted to remove any pre-diagnosed skin cancers under the governance arrangements of the skin cancer MDT. Such models should be encouraged to flourish nationally to aid the increasing burden of skin cancer work, facilitate shorter waiting times, exchange ideas between primary and secondary care and allow care closer to home which patients and their relatives appreciate.” Dr Neil Shroff, Accredited GPwSI Skin Cancer*

#### Expert Group Recommendation 4

**GPs should be sufficiently incentivised to train as GPwSIs in order to build a workforce with the necessary expertise in skin cancer. This could include financial incentives and a place on the local MDT.**

Even with increased specialisation and more robust education and training in skin lesion recognition, in the short-term it is still likely that in one particular area there will be one to two GPs who possess the necessary skills to assess a patient with suspected melanoma. It was suggested by some members of the group that in order to combat a possible ‘post-code lottery’ in access to skin cancer services in primary care, every large group GP practice should have at least one practitioner well-trained in skin lesion recognition, including the use of dermoscopy.

The role that GPwSIs and Level II practitioners in secondary care when working alongside their colleagues on the MDT will be covered in further detail in Chapter 4.

<sup>10</sup> NHS, Revised Guidance and competences for the provision of services using GPs with Special Interests (GPwSIs): Dermatology and skin surgery (2011)



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# Chapter 3

## Dermatology

### Group Membership

Dr Jerry Marsden Consultant Dermatologist, University Hospital Birmingham NHS Foundation Trust; Chair, Melanoma Study Group

Dr Dafydd Roberts Consultant Dermatologist, Swansea NHS Trust

Saskia Reeken Cancer Nurse Specialist Skin Cancer and Dermatology, Kingston Hospital NHS Trust; Skin Cancer Group Chair, British Dermatological Nursing Group

### Introduction

In 2010, the British Association of Dermatologists (BAD) published its revised guidelines for the management of cutaneous melanoma. These guidelines, alongside NICE's *Improving Outcomes Guidance (IOG) for People with Skin Tumours including Melanoma*, remain the principal reference point for dermatologists in melanoma care. With one exception (the involvement of level 2 practitioners in excising suspicious lesions), the Expert Group has focused its attention on areas where compliance and adherence to these guidelines needs strengthening, particularly where poor compliance impedes early diagnosis or results in poor patient outcomes. The group's recommendations cover referral and triage; excision; diagnosis; and follow-up, highlighting elements of existing guidance that must be consistently applied in practice but are, at present, not being done so to a sufficiently high standard.

### Discussion

#### Referral and triage

As discussed in Chapter 2, the Urgent Suspected Cancer (USC) referral system (Two Week Wait) appears to be working well for patients with suspected melanoma, with the majority of patients referred on to dermatology within the two week timeframe. The group acknowledged that, in the main, delays occur in patients who are referred to dermatology via routes other than the USC system or where delayed referral occurs in primary care.

Saskia Reeken, Cancer Nurse Specialist in Skin Cancer and Dermatology, noted that delays can not only result in a thicker melanoma and a potentially poorer prognosis, but can also have a significant impact on the psychological wellbeing of the patient.

*“Delays in the pathway in primary care can damage the trust that the patient has in their GP and in some instances can result in an inability for the patient to move psychologically forwards in their treatment journey.” Saskia Reeken*

In order to address these unwarranted delays, the group discussed ways in which the triage process could be improved using teledermatology; helping GPs to make appropriate referral decisions that will ultimately improve patient access to early diagnosis.



## What is teledermatology?

Teledermatology is defined by NICE as: *“the use of digital images, together with relevant patient information, as a means of aiding referral of patients with skin problems from primary to secondary care.”*<sup>1</sup>

The guidance recommends *“...more research into the most effective way of utilising teledermatology to triage patients with suspicious skin lesions, looking at all aspects of its use including clinical accuracy, cost-effectiveness, patient confidentiality and patient acceptability.”*<sup>1</sup>

The use of photography as a means of aiding triage has been trialled in a number of clinical settings including Cardiff, Leith, Glasgow and Oxford. When a GP is referring a patient on to dermatology, they are encouraged to attach a photograph of the suspicious lesion. This could be an electronic attachment to an email or a hard copy photograph that is enclosed with the referral letter. The group acknowledged that the varying quality of the photographs could undermine its utility in assisting diagnosis, but agreed that there are significant benefits in helping the dermatologist decide whether or not the lesion requires urgent attention.

There are obvious challenges in the implementation of such a recommendation including access to the necessary equipment and regulating the quality of the photograph, both of which will be dependent on the resources of individual GP practices. As such the group agreed that whilst it would not be possible to make photographic images a mandatory part of the referral process, it should be encouraged where possible. The group noted that research on the use of smart phone technology in teledermatology has been carried out. Several studies have assessed the use of “apps” and digital imaging in order to aid the recognition and diagnosis of suspicious lesions, but the technology is in its infancy and the studies have been inconclusive.<sup>2</sup>

When implementing such referral mechanisms, it is also important that the detail of the preferred route to referral is agreed between the primary and secondary care providers to ensure continuity of care. This will be particularly important as the NHS moves towards the provision of services by Any Qualified Provider (AQP) when the integration of state and private services will need to be monitored very closely.



### Quality Statement

Patients newly diagnosed with stage 2B or higher melanoma (or stage  $\geq 1B$  if SLNB is offered) should be referred to a SSMDT in line with current national guidance.



### Quality Statement

People with a suspected melanoma, when being referred by a GP are done so within the Urgent Suspected Cancer (USC) framework (Two Week Wait), and where possible a photograph of the suspected lesion should be taken, in order to aid triage.

The British Association of Dermatologists (BAD) is currently working with a number of organisations to develop a set of teledermatology standards which will include a close examination of phototriage. These are due to be published in September 2012.

## Excision

In line with the 2010 BAD Guidelines, the group recommends that:

*“A lesion suspected to be melanoma, or where melanoma needs to be excluded, should be photographed, and then excised completely. The axis of excision should be orientated to facilitate possible subsequent wide local excision; generally on the limb this will be along the long axis. If uncertain, direct referral to the multidisciplinary team (MDT) will allow appropriate planning for future surgery. The excision biopsy should include the whole tumour with a clinical margin of 2 mm of normal skin, and a cuff of fat. This allows confirmation of the diagnosis by examination of the entire lesion, such that subsequent definitive treatment can be based on Breslow thickness.”*<sup>3</sup>

The group saw no reason to question the current recommended excision margins and therefore recommends that this existing guidance be adhered to. It was acknowledged that the Melanoma Study Group (MSG) is due to publish further analysis of its excision margin trial data in due course, which will inform any future necessary changes to the guidance.

<sup>2</sup> Lamel, S. A., Haldeman, K. M., Ely, H., Kovarik, C. L., Pak, H., & Armstrong, A. W., Application of mobile teledermatology for skin cancer screening, Journal of the American Academy of Dermatology (2012), 11:957-969.

<sup>3</sup> British Association of Dermatologists, Revised UK guidelines for management of cutaneous melanoma (2010) p. 241



Whilst the detail of the guidance was not questioned, some members of the Expert Group reported that its implementation was cause for concern. Members reported that in spite of the guidance clearly stating that “a lesion suspected to be melanoma....should be photographed, and then excised completely”, in some areas melanomas are incised or punch-biopsied, rather than completely excised.

Professor Julia Newton-Bishop noted that an implementation audit in Yorkshire had shown that this full excision guidance is clearly not complied with:

*“When melanomas are treated either inadvertently in primary care, or by dermatologists, then an unacceptable number of them are incised or punch-biopsied, rather than completely excised. Failure to excise melanomas in their entirety may prejudice staging by precluding accurate measurement of the Breslow thickness and may result in diagnostic error as a result of sampling error. The proportion of sub-optimal biopsies is higher in primary care, largely because they are inadvertent biopsies – they’re not thought to be melanoma at the time – but it is one of the issues within the guidelines which is a problem.” Professor Julia Newton-Bishop*

The 2010 BAD Guidelines state that diagnostic shave biopsies “should not be performed” as they may lead to incorrect diagnosis, and for the same reasons, partial removal of naevi for diagnostic purposes “must be avoided”. The guidelines, however, do qualify this recommendation for complete excision by stating that:

*“incisional or punch-biopsy is occasionally acceptable, for example in the differential diagnosis of lentigo melanoma (LM) on the face or acral melanoma, but there is no place for either incisional or punch biopsy outside the skin cancer MDT (Level III).”<sup>4</sup>*

The group has therefore reaffirmed the BAD’s guidance on this procedure and stated that in order to avoid incorrect diagnosis due to sampling error and to ensure that accurate pathological staging of the lesion is possible, people with a suspected melanoma should have the lesion excised completely.



### Quality Statement

People with a suspected melanoma should have the lesion excised completely, as incisional, punch biopsy, or curettage of melanoma may prejudice the measurement of Breslow thickness and may also lead to incorrect histopathological diagnosis as a result of sampling error.

## Diagnosis

In line with the 2010 BAD Guidelines, the group agrees that following a full history of the lesion, a detailed examination of the findings should include a differential clinical diagnosis, a clinical photograph and histopathology. The histopathology report should include the site of the tumour; type of surgical procedure (exision or re-excision, incision biopsy, punch biopsy); and any other relevant clinical information.<sup>5</sup> Crucially, the group recommends that all information gathered during the early stages of investigation should be shared with the Local MDT and Specialist Skin Cancer MDT to facilitate an integrated decision-making process and ultimately a final diagnosis free from error or inconsistency.

<sup>4</sup> British Association of Dermatologists, Revised UK guidelines for management of cutaneous melanoma (2010) p. 241

<sup>5</sup> British Association of Dermatologists, Revised UK guidelines for management of cutaneous melanoma (2010) p. 241



**Quality Statement**

People with suspicious lesion(s) have a full history of the lesion(s) taken, followed by a detailed examination of the findings, including: a differential clinical diagnosis; a clinical photograph; and histopathology. All information gathered in the process of diagnosis is available to an LSMDT or to a SSMDT to minimise the risk of error in agreeing upon the final diagnosis.

**Follow up**

The BAD Guidelines recommend that people with a family history of three or more melanomas and people who have atypical mole syndrome, should be referred to a clinical geneticist or to specialised dermatology services for counselling.<sup>6</sup> Central to monitoring the health of these high-risk individuals is the storage of imaging from dermoscopy (epiluminescence microscopy). Epiluminescence microscopy is a non-invasive technique that, by use of oil (or gel) immersion, makes sub-surface structures of skin accessible for *in vivo* microscopic examination and thus provides additional criteria for the diagnosis of pigmented lesions. The *Improving Outcomes Guidance (IOG) for People with Skin Tumours including Melanoma* recommends that:

*“Medical photography has a special role to play in the surveillance for patients with atypical naevi. Therefore, all departments treating skin cancer should have access to high-quality medical photography and storage of medical images.”<sup>7</sup>*

Testimony from the Expert Group suggests that compliance in this area is poor and as such has reaffirmed the importance of storing baseline dermoscopy images to aid the ongoing monitoring of high-risk patients.



**Quality Statement**

Melanoma patients with a family history of melanoma or atypical naevus syndrome will require longer term supervision by specialist services which have access to photography using dermoscopy.

**Evidence Sources**

- British Association of Dermatologists, *Revised UK Guidelines for the management of cutaneous melanoma* (2010) [http://www.bad.org.uk/Portals/\\_Bad/Guidelines/Clinical%20Guidelines/Melanoma%20guidelines%202010.pdf](http://www.bad.org.uk/Portals/_Bad/Guidelines/Clinical%20Guidelines/Melanoma%20guidelines%202010.pdf)
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<sup>6</sup> British Association of Dermatologists, Revised UK guidelines for management of cutaneous melanoma (2010) p. 241

<sup>7</sup> British Association of Dermatologists, Revised UK guidelines for management of cutaneous melanoma (2010) p. 62



## Chapter 4 Surgery

### Group Membership

Prof. Barry Powell	Consultant Plastic Surgeon, St George's Healthcare NHS Trust
Prof. Meirion Thomas	Senior Surgeon, Royal Marsden NHS Foundation Trust
Catherine Wheelhouse	Skin Cancer Clinical Nurse Specialist, Bradford Teaching Hospital NHS Trust

### Introduction

In the main, melanoma, when detected early, is successfully treated by surgical intervention. Surgeons (usually specialist reconstructive surgeons) are pivotal members of the multi-disciplinary team (MDT), but there was a strong consensus that MDTs working in secondary care should endeavour to work closely with the LSMDT and their primary care colleagues in order to facilitate an integrated care pathway. The Expert Group has made a number of recommendations that explore the various surgical procedures that should be taken into consideration when planning a melanoma patient's treatment pathway, including sentinel lymph node biopsy (SLNB), Isolated Limb Infusion (ILI) and stereotactic neurosurgery. SLNB is a highly controversial issue and its controversy was borne out in the debate that took place amongst members of the Expert Group. However, it was agreed that it should be discussed with patients so that they can make a choice, based on a clear understanding of the risks and benefits, as to whether they would like to undergo the procedure.

### Discussion

#### Investigations

##### *Sentinel Lymph Node Biopsy (SLNB)*

In 2010, the Melanoma Taskforce's *2015 Skin Cancer Visions* report discussed the usefulness of SLNB as a staging tool. The report recommended that "national standards, perhaps NICE guidance, on the use of SLNB, 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."<sup>1</sup>

The Expert Group discussed at great length the role of SLNB and its value within the patient pathway. Patient access to SLNB varies widely, depending on whether a unit offers the procedure and has surgeons to perform it. SLNB has no established survival value but is an effective staging tool. There does remain however considerable uncertainty about whether it is a cost effective intervention. Indeed, it was noted by a member of the group that SLNB may, in the future, be superseded or augmented by molecular prognostic and predictive tests for melanoma patients.

<sup>1</sup> Melanoma Taskforce, *2015 Skin Cancer Visions* (2010), p.21





## What is Sentinel Lymph Node Biopsy (SLNB)?

A surgeon injects a small amount of dye and a mildly radioactive tracer into the area where the melanoma was removed. The dye/tracer drains away from the area into the lymph glands. The surgeon identifies the first draining node (the sentinel node) using the radioactive tracer in the course of a scan and he/she locates the node during the operation using the blue dye. The surgeon removes one or more of these nodes and sends them to the lab to see if they contain melanoma cells.

If the lab finds that none of the lymph nodes contain melanoma cells, the patient will not need to have any more nodes removed and will not usually need any further tests. If the sentinel lymph nodes contain melanoma cells, there is a risk that other lymph nodes may also contain melanoma cells. The patient will usually need to have a further operation to remove the other lymph nodes in the area.

Source: Adapted from *Cancer Research UK (2012)*

The main argument for those challenging the routine use of SLNB as the principal staging tool available to patients is the absence of data on SLNB that supports its efficacy. A study by A. Mitra et al concluded that “Using clinico-pathological features (thickness, mitotic count, ulceration, vessel invasion, site, age and sex) gave a better AUC (area under the curve) to predict relapse (71.0%) and survival (70.0%) than SLNB status alone (57.0, 55.0%).”<sup>2</sup>

There was also considerable debate as to the validity of the evidence on which SLNB’s value is based and the research methodology used to date. According to the 2009 American Joint Committee on Cancer (AJCC) staging system, the 10 year survival rate for Stage IIB and Stage IIC melanoma is 55 per cent and 40 per cent respectively, and for Stage IIIA 68 per cent. However, the thicker tumours that are SN-negative can have a worse prognosis than tumours 1 mm or greater that are SN-positive, thereby challenging the prognostic argument.

In the interim SLNB is widely used internationally to stage disease in patients with melanoma. A survey carried out by the Melanoma Taskforce (2011) showed that 75 per cent of Cancer Networks in England and Wales utilise SLNB as a staging tool for patients with melanoma, with a further three SSMDTs reported to be commencing the technique in the near future.<sup>3</sup>

The 2010 *Revised UK Guidelines for the management of cutaneous melanoma* published by the BAD state that SLNB “can be considered in Stage 1B melanoma and upwards in Specialist Skin Cancer Multidisciplinary Teams.”<sup>4</sup> It goes on to state that, “SLNB is a staging procedure with no proven therapeutic value. Surgical risks of SLNB, and of a false-negative result, should also be explained.” It is therefore possible to infer that patients have the right to be offered SLNB as a tool by which to stage the progression of their disease. There was consensus amongst the group that SLNB has *some* utility, but there was considerable debate as to the extent of its utility or where SLNB should sit within the pathway, if at all.

Some members suggested that SLNB should only be offered to patients for the purposes of determining eligibility for trials of adjuvant therapy approved by the European Organisation for Research and Treatment of Cancer (EORTC) and National Cancer Research Network (NCRN).

However, concerns were raised as to the challenges of implementing this system:

- If SLNB is provided *before* consent for any trial is obtained, it must be equitably available to all patients with the appropriate stage of melanoma, irrespective of whether they have expressed an interest in a trial. If not, there is a risk that SLNB could be seen as coercive.
- If the procedure is provided *after* consent for the trial has been obtained, it must be done as part of the trial protocol and thereby only available to those entering the study.

This proposal was further challenged by members who felt it would be wrong to deny informed non-trial patients equitable access to a procedure that can provide good prognostic information that aids the stratification of patients.

There was a degree of consensus amongst members that if SLNB is to remain a routine intervention in the melanoma care pathway, then patients must be

<sup>2</sup> A Mitra et al., Melanoma sentinel node biopsy and prediction models for relapse and overall survival, *British Journal of Cancer* (2010), 103(8):1229-36.

<sup>3</sup> Melanoma Taskforce, *Variations in Melanoma Survey* (2011)

<sup>4</sup> British Association of Dermatologists, *Revised UK Guidelines for the management of cutaneous melanoma* (2010), p. 255



informed of the risks and benefits of the procedure, and alternative staging tools available. Access to standardised information that clearly sets out the risks and benefits of the procedure will be central to ensuring that the right decision is made for each patient.



### Quality Statement

Although sentinel lymph node biopsy (SLNB) has no established survival value, it is a staging tool for melanoma. People with primary melanoma should be given a clear description of this procedure, its risks and benefits and information on appropriate clinical trials. Those who choose to have a SLNB should be referred promptly to the centre of their choice.

## What is stereotactic radio-surgery?

Stereotactic radio-surgery delivers a very precise dose of radiation. Stereotactic means locating a point (in this case the position of the tumour in the brain) using three-dimensional coordinates. Stereotactic radio-surgery ensures that the maximum amount of radiation is aimed at the tumour and that surrounding tissue is not exposed. It may be given as a single dose or delivered over several sessions. The procedure is performed under local anaesthetic, but the scalp is numbed. A lightweight frame is attached to the scalp, and a series of scans accurately pinpoint the position of the tumour.

Source: NHS Choices (2010)

## Stereotactic radio-surgery & Isolated Limb Infusion (ILI)

The group discussed access to appropriate specific interventions for patients with melanoma. It was agreed that people with brain metastases should have access to stereotactic surgery, but it was suggested that current access to the treatment is highly variable across the country. This was a cross-cutting issue for those in the oncology and surgery core teams, but there was broad consensus that it was important for patients with brain metastases to have access to the full range of therapeutic options, including stereotactic radio-surgery.

Access for patients to Isolated Limb Infusion (ILI) and Isolated Limb Perfusion (ILP) was also discussed by the group and it was agreed that the provision of the treatment was patchy in some places around the country, and that patients should have access to the procedure where appropriate.

## What is Isolated Limb Infusion (ILI) and Isolated Limb Perfusion (ILP)?

Isolated limb infusion (ILI) is a form of regional chemotherapy. This is a way of delivering high dose chemotherapy just in one arm or leg, without the drugs circulating through the rest of the body. It is only used if the melanoma has come back in the same limb in which it started and if it cannot be safely and effectively removed by surgery. Fine tubes are inserted in the limb blood vessels, the limb is then cut off from the rest of the body using a tourniquet, and a very high dose of chemotherapy is administered to the limb. This is safe because the drugs stay in the limb – they cannot affect the rest of the body.

Isolated Limb Perfusion (ILP) is similar in principal; however, it is a bigger operation because the surgeon puts tubes into the blood vessels that carry blood in and out of the limb. The blood supply to the limb is cut off from the rest of the circulation and the blood is provided with oxygen using a heart-lung machine. This allows for longer periods of exposure to chemotherapy, and stronger mixtures of drugs to be used. This is useful for very large lumps that may not be targeted effectively by ILI. Chemotherapy is then added to the limb blood supply in a similar way to ILI, but it is circulated around the limb using a pump. The machine will also warm the blood. After a short time, the surgeon reconnects the blood vessels and your blood circulation goes back to normal.

Source: Adapted from Cancer Research UK



**Expert Group Recommendation 5**

**Patients with brain metastases should have access to the full range of therapeutic options including stereotactic radio-surgery.**

## Management of node metastases

In line with the BAD's 2010 Guidelines, the group recommends that, "Superficial inguinal LND (SLND) should be considered in the presence of a single clinically involved inguinal node or femoral triangle node; a single positive superficial inguinal sentinel node (Level Ib, Grade A)."

*"Pelvic lymph node dissection (PLND) should be considered in the presence of more than one clinically palpable inguinal and/or femoral triangle node/s; CT ultrasound evidence of more than one inguinal and/or femoral triangle node/s, or of pelvic node involvement; more than one microscopically involved node at SLNB; a conglomerate of inguinal or femoral triangle lymph nodes; microscopic or macroscopic involvement of Cloquet's node (Level III, Grade B)."*<sup>5</sup>

There is some evidence to suggest that some patients with unsuspected low volume pelvic node metastases could gain a survival advantage from early Combined Lymph Node Dissection (a combination of the SLND and PLND procedures) rather than SLND or PLND alone<sup>6</sup>. Future practice will have to take account of these findings should they prove that patients will derive a survival advantage from routine rather than selective CLND. For example, further training will be required in order to up-skill surgeons in the application of the procedure.

## Enhanced Recovery Programme

### What is the Enhanced Recovery Programme?

The Enhanced Recovery Programme (ERP) is a Quality and Improvement Tool designed by the NHS Institute for Innovation and Improvement. Originally known as the multi-modal approach, it is also known as 'fast-track surgery'.

There are four elements of the ERP:

- Pre-operative assessment, planning and preparation before admission.
- Reducing the physical stress of the operation.
- A structured approach to immediate post-operative and during (peri-operative) management, including pain relief.
- Early mobilisation.

Evidence suggests that the programme: reduces the length of time the patient is in hospital; increases the number of patients treated (if there is the demand); or reduces the level of resources if necessary; and delivers a better staffing environment.

*Source: NHS Institute for Innovation and Improvement (2008)*

<sup>5</sup> British Association of Dermatologists, Revised UK Guidelines for the management of cutaneous melanoma (2010), p. 247

<sup>6</sup> Badgwell et al, Prospective Assessment of Post-operative Complications and Associated Costs Following Inguinal Lymph Node Dissection (ILND) in Melanoma Patients, *Annals of Surgical Oncology* (2007), 14:2867-2875



The Enhanced Recovery Programme (ERP)  
*National Institute for Innovation and Improvement (2008)*

**Training and learning: staff do particular tasks in a particular order**

**Improved processes and room layout**

**Procedure specific care plans**

<p><b>Improved pre-operative care</b></p> <ul style="list-style-type: none"> <li>• Pre-op assessment</li> <li>• Consent and information</li> <li>• Plan and prepare discharge</li> <li>• Patient prepares organs, joints, etc for surgery</li> </ul>	<p><b>Reduced physical stress of operation</b></p> <ul style="list-style-type: none"> <li>• Local anaesthesia</li> <li>• Surgical technique</li> <li>• Care around surgery</li> <li>• Pharmacologist</li> </ul>	<p><b>Increased post-operative comfort</b></p> <ul style="list-style-type: none"> <li>• Effective pain relief and prophylaxis for nausea and vomiting</li> </ul>	<p><b>Improved post-operative care</b></p> <ul style="list-style-type: none"> <li>• Early mobilisation</li> <li>• Minimal use of drips, drains and catheters</li> <li>• Oral nutrition</li> <li>• Patient held plans</li> </ul>
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**Patients recover faster with better outcomes**

**Monitor**  
 Morbidity, readmission rates, safety, cost and length of stay, patient satisfaction, waiting times, application of evidence based care (care bundles)

It was suggested that the ERP could be utilised in the management of surgical patients in melanoma. In particular, members discussed the potential opportunity to use this programme in order to manage the length of stay in hospital and reduce the risk of complications and readmission. Surgery for melanoma is not currently covered by the ERP, but it was noted that providers who identify and treat melanoma patients (elective) are well placed to utilise the pre-operative assessments, planning and preparation mechanisms, as outlined in the ERP, to streamline the patient pathway.

**Expert Group Recommendation 6**

**Applying the Enhanced Recovery Programme to melanoma could improve patient outcomes and experience and the cost effectiveness of care. Settings where melanoma patients are identified as elective rather than emergency patients, would be best placed to lead on the implementation of the ERP in melanoma.**

**Ways of working**

As discussed in Chapter 2, the role of GPwSIs and Level II practitioners in the diagnosis and treatment of melanoma was a topic of considerable debate amongst the group, reflecting the wider debate currently ongoing within the clinical community. It was agreed that appropriate training and education programmes should be put in place to support the professional development of GPs in the identification and diagnosis of melanoma in primary care. It was also agreed that there should be closer working between GPwSIs and MDTs in order to challenge the divide between primary and secondary care and to ensure that MDTs can provide the necessary clinical governance for GPwSIs working within a secondary care setting. In particular, the group welcomes the involvement of appropriately trained and accredited Level II practitioners in the local excision of suspicious pigmented lesions but only when supervised by the MDT.

Some concerns were expressed by members of the group that current ways of working between SSMDTs and LSMDTs need to be revised. For example, NICE

- Foreword
- Introduction
- Quality Statements & Pathway Map
- Primary Care
- Dermatology
- Surgery
- Oncology
- Survivorship & End of Life
- Service Design & Implementation
- Glossary



Guidance recommends that “patients needing nodal dissection including sentinel node biopsy (SLNB)” should be referred to the SSMDT by the LSMDT<sup>7</sup>. The group was made aware that in some instances the stringent implementation of the NICE Guidance has led to a number of unintended consequences. Even in areas where there are sufficiently skilled plastic surgeons and the appropriate structures in place to facilitate SLNB by the LSMDT, patients are still being referred for care outside of their local area. Some members were concerned that this will have a detrimental impact on the skill level of local plastic surgeons and add unnecessary delays to the treatment pathway. The group as a whole therefore recommends that closer working between the SSMDTs and LSMDTs could address this problem by encouraging the delivery of a holistic, timely and viable treatment plan.

#### Expert Group Recommendation 7

**Closer working between the Local Hospital Skin Cancer Multi-Disciplinary Team (LSMDT) and the Specialist Skin Cancer Multi-Disciplinary Team (SSMDT) will ensure the safe, equitable and co-ordinated delivery of services with the patient at its centre.**

## Further Research

The group was made aware of evidence published by the National Cancer Intelligence Network (NCIN) that shows there is a large reduction with age of the percentage of patients receiving a major resection, even for patients over 50 years old. Skin tumours were not included in this study, but given that the burden of melanoma falls heaviest in the over-65s, the group recommends that this study be re-run for melanoma.<sup>8</sup>

#### Expert Group Recommendation 8

**Research should be carried out to ascertain trends in the age of patients with melanoma who receive a major resection. This would contribute to our understanding of the likelihood of patients over 50 years old opting for surgical interventions (i.e. the age group where the burden of disease is heaviest).**

## Evidence Sources

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<sup>7</sup> NICE, *Improving Outcomes for People with Skin Tumours including Melanoma* (2006), p.58

<sup>8</sup> The National Cancer Intelligence Network's study in 2010 undertook national analyses of major surgical resections for thirteen cancer sites, with results by age group and deprivation index. [http://www.ncin.org.uk/publications/data\\_briefings/major\\_resection.aspx](http://www.ncin.org.uk/publications/data_briefings/major_resection.aspx)





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# Chapter 5 Oncology

## Group Membership

Dr James Larkin	Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust
Dr Paul Lorigan	Consultant Medical Oncologist, Christie NHS Foundation Trust
Gill Nuttall	Founder, Factor50

## Introduction

Achieving equitable access to treatments for advanced disease is a significant challenge in the NHS, as was acknowledged by the Government's *Improving Outcomes: a strategy for cancer*. Published in January 2011, the strategy highlighted evidence that the UK is a relatively low user of some cancer drugs and that clinicians have not always had the freedom to prescribe the drugs that they feel could benefit their patients. Equitable access was identified by the group as a key priority, in particular the way in which commissioners and clinicians should be working to ensure that patients have access to all available, clinically appropriate therapeutic options. There was a clear consensus amongst the group that recent advances in the way in which melanoma is treated have been brought about by trial based research. The group agreed that further improvement will only come when clinical practice is strongly embedded in clinical research.

## Discussion

### Ways of working

A key challenge for members of the multi-disciplinary team (MDT) is coordinating patient care effectively, particularly when optimal patient care relies on so many clinicians being part of the diagnosis, treatment and management of each individual patient.

### What is a multidisciplinary team (MDT)?

A multidisciplinary team (MDT) is a team of health professionals who work together to decide on the best way to manage a patient's care. In melanoma the MDT can include many different health professionals including dermatologists, surgeons (including plastic (reconstructive) surgeons), oncologists, radiologists, specialist nurses, GPs with a special interest in skin cancer, physiotherapists, psychologists, lymphoedema services, occupational therapists, cosmetic camouflage advisers and histopathologists.

There are 2 levels of MDT for melanoma. They are the Local Hospital Skin Cancer Multidisciplinary Team (LSMDT) and a Specialist Skin Cancer Multidisciplinary team (SSMDT). LSMDTs are usually based in cancer units in district general hospitals. SSMDTs are more likely to be located in larger hospitals that have cancer centres, or plastic surgery centres. Everyone with suspected melanoma is seen by a member of one of these teams.

Source: *Cancer Research UK (2012)*



For patients with high risk primaries or metastatic melanoma it is especially important that all of the core clinical members of the melanoma MDT are in a position to contribute to the planning of a patient’s care in an optimal manner. Therefore in order to facilitate clinical discussion and decision-making in this timely fashion, the working group placed significant emphasis on parallel clinic working.

The group felt very strongly that parallel clinics are a vital step in the improvement of patient outcomes and are critical if truly integrated care is to be achieved in melanoma. Parallel clinics allow for all of the core members of the MDT to be on hand for the patient at the same time, within the same locality. Evidence from members of the Expert Group suggests that this is working well in a number of locations including at Leeds Teaching Hospitals Trust and at the Royal Marsden Hospital in London. Indeed, it was suggested that parallel clinic working is becoming increasingly common but the group felt that it was important to make a clear statement about its importance as a key marker of high quality care.

## Parallel Clinic Working: Leeds Teaching Hospitals NHS Trust

*“The specialist melanoma MDT in Leeds is a fully integrated melanoma service. Patients referred to the service have their pathology and radiology discussed. The MDT considers the most appropriate treatment and the patient’s suitability for clinical trials. Following this, in clinic, a patient will be seen by their consultant but as part of a large joint clinic with dermatologists, medical and clinical oncologists and plastic surgeons attending. This ensures a ‘one stop clinic’ approach, where patients with new problems can be seen immediately by consultants with the relevant expertise. A similar process is in place for the specialist non-melanoma clinic in Leeds and also for other centres in England.” Howard Peach, Consultant Plastic Surgeon*

<http://www.bapras.org.uk/listing.asp?id=1113>



### Quality Statement

People with confirmed melanoma should have access to a multi-disciplinary team comprising all specialist core members with clinics running simultaneously to facilitate timely clinical discussion and decision making.

## Clinical trials

### Equitable Access

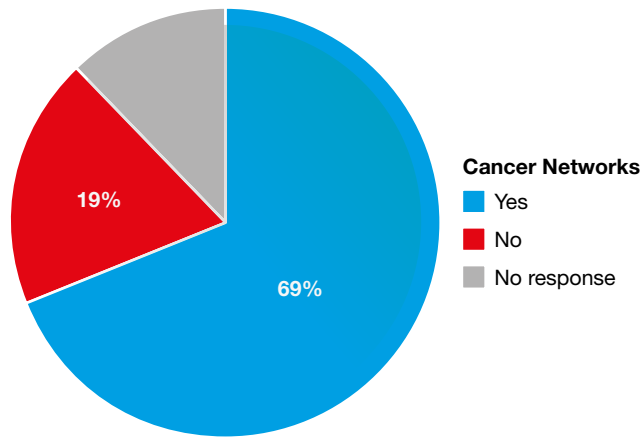
Major advances in the treatment of melanoma have been largely trial based and there was a clear consensus amongst the group that further improvement in patient outcomes will only occur when clinical practice is strongly embedded in clinical research. The Melanoma Taskforce’s 2015 *Skin Cancer Visions* report recommended that “patients should have equitable access to information on all clinical trials for new treatments in development and be given the choice to take part in them.” However, a survey carried out by the Taskforce in autumn 2011 clearly demonstrated that equitable access remains a challenge for many centres with almost 20 per cent of Cancer Networks reporting that they do not make patients aware of clinical trials taking place in another Network that may be appropriate for them.<sup>1</sup> As such, the Expert Group agreed that a strong focus must be placed on recruiting patients to clinical trials to ensure that momentum in clinical research is not lost.

Whilst this should already be standard practice, the group suggested that it is not happening as often as it should. If there are no trials for which a patient is eligible locally, they should be given access to trials running in a different Network. During this discussion the group acknowledged the challenges of opening up access to trials, with significant variation in the way in which Networks manage cross-network



Are patients routinely made aware of clinical trials that may be appropriate for them that are taking place within another Network?

Source: Melanoma Taskforce (2011)



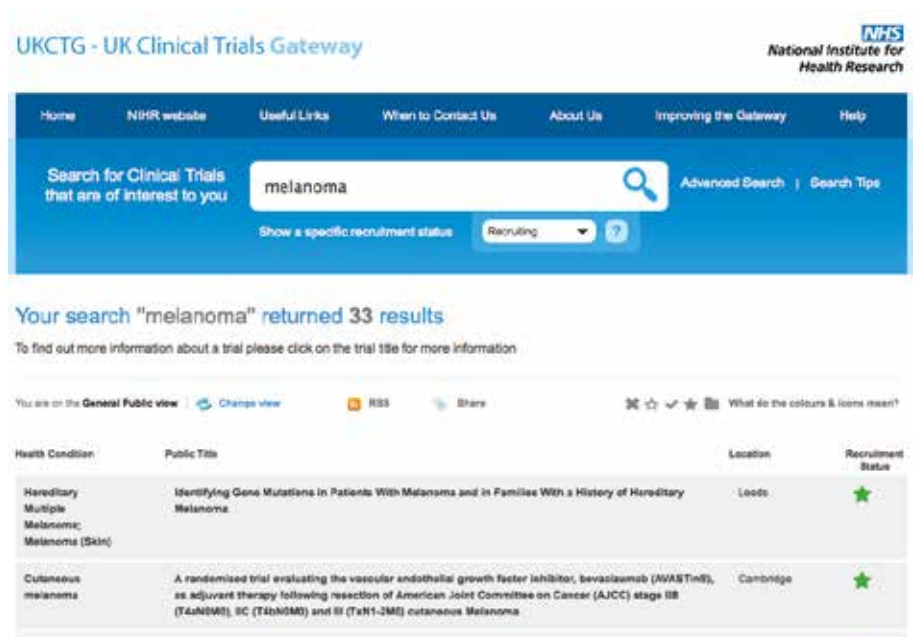
referral. In some instances, patients are not referred to a trial unless they proactively seek it out either by referring themselves or by approaching their clinician.

Following this discussion, some members of the group suggested that keeping patients informed of new trials is a challenge for clinicians as they are constantly opening and closing and it is difficult to remain abreast of when and where they are happening. The geographical spread of trials was also identified as an issue, with larger centres often being favoured to host trials over the smaller facilities. The National Cancer Research Network (NCRN) is currently working to ensure that more trials are available to more centres by promoting innovation in smaller 'green shoot centres'. The Department for Business, Innovation and Skills (DBIS) has acknowledged that strengths within the NHS and research sector are under-utilised, and has therefore committed to take action.

*“The UK can do much more to harness opportunity that exists in the NHS. There is huge potential to better support the adoption and diffusion of innovation, to access patient data to inform the development phase, and to involve patients in trials and early access schemes for the treatment of chronic diseases, such as cancer.”*  
Strategy for UK Life Sciences, Department for Business Innovation and Skills 2

As part of this Life Sciences strategy, the Government has also re-launched the National Institute for Health Research's UK Clinical Trials Gateway. This online portal is designed to “open up information about clinical trials to enable the public to get involved and so that patients can find out about clinical trials that may be relevant to their condition.”<sup>3</sup>

Source: NHS National Institute for Health Research



2 Department for Business Innovation and Skills, Strategy for UK Life Sciences (2011), p.5  
3 UK Clinical Trials Gateway (UKCTG) <http://www.ukctg.nihr.ac.uk/default.aspx> [Accessed on 29.05.12]



Whilst other trials are available, the group has favoured participation in trials that are approved by the NCRN as they ensure a basic, minimum standard of quality and contribute to a wider, coherent research strategy. The group is also keen to see a shift in access to trials for Teenagers and Young Adults. Many trials are currently closed to young people, and as Simon Davies of the Teenage Cancer Trust noted, the way in which a trial is designed can limit access for young people.

*“There are many trials that currently exclude Teenagers and Young Adults both in paediatric and adult care - not only in melanoma, but right across the board. The Teenage Cancer Trust are trying to get trials designed to extend to the group, but this is proving to be very difficult.” Simon Davies, Chief Executive, Teenage Cancer Trust*



### Quality Statement

People with melanoma, including Teenagers and Young Adults (16 -24), are offered the opportunity to take part in NCRN approved clinical trials for which they are eligible within the NHS, irrespective of where the trial is taking place. Teams should demonstrate contribution to NCRN trials in the preceding 3 years.

### Patient accrual rates

A second challenge highlighted by the group is the way in which trial recruitment is monitored, measured and evaluated. Patients may be offered access to a trial but then may decide that they do not want to pursue it or find that they are not eligible. Where this occurs, data are not collected and will not be included in a centre’s NCRN accrual rates, even though the patient has been informed of the appropriate trials. The group agreed that the collection of data on where clinical trials are offered and where participation is secured would be a valuable resource, but further research is required into how this can be collated, published and audited efficiently and effectively.

### Expert Group Recommendation 9

**Further research should be carried out on how data should be collected on where trials are offered and where participation is secured. This research should also look at how the data should be published and audited.**

## Genotyping

The genotype is the genetic makeup of a cell; genotyping allows clinicians to see the differences between one individual’s DNA sequence when compared to another. Genotyping of tumours does not necessarily tell the oncologist whether or not a cancer was or could be potentially inherited, but identifies gene mutations, such as the *BRAF* mutation, which can then inform subsequent decisions about treatment.

Genotyping of tumours is carried out to allow for the use of targeted therapies. The development of such therapy for melanoma is still in its infancy and the tests required for therapeutic testing will likely change relatively quickly over the years. Concerns were therefore raised that by offering genotyping to patients with anything less than Stage IIIB might use up their tumour DNA unnecessarily. Those patients whose melanoma is no more advanced than Stage IIIB are, in any case, less likely to relapse. The group concluded that at present it was therefore most appropriate to recommend the procedure only for people with Stage IIIB melanoma or greater. The MDT will also then have access to the DNA data of those who are most likely to relapse and this will inform any future decisions with regards to that patient’s treatment plan.

Members of the group also noted that the psychological implications for the patient should be taken into consideration. It was suggested that patients who have the *BRAF* mutation will have access to additional treatment options, yet those patients





who do not have the mutation could feel they are worse off as those treatment options are closed off to them.



**Quality Statement**

People with  $\geq$ Stage IIIB melanoma, should be offered genotyping of their melanoma to allow planning of systemic treatment by the multidisciplinary team.

**Treatment options for advanced disease**

The Government report, *Improving Outcomes: a strategy for cancer*, published in January 2011, admitted that “there is evidence that the UK is a relatively low user of some cancer drugs and that patients may be treated more conservatively than in other countries. It is clear that clinicians have not always had the freedom to prescribe the drugs that they feel could benefit their patients. Clinicians and patients have repeatedly expressed frustration with this.”<sup>4</sup> The new strategy cited the findings of the review conducted by the National Clinical Director for Cancer, Professor Sir Mike Richards, into international variations in drug usage, which showed that in cancer in the UK the ‘use of new drugs is relatively low in comparison with international averages.’<sup>5</sup>

In 2010 the Melanoma Taskforce highlighted the fact that metastatic melanoma is notoriously hard to treat, and until very recently there had not been any breakthroughs that significantly increased patient survival. However, the *2015 Skin Cancer Visions* report recommended that patients “should have equitable access to new treatments as they become available in the NHS to ensure that UK melanoma rates do not fall behind other comparable countries or tumour types.”<sup>6</sup>

A key part of the Government’s cancer strategy, which aims to save an ‘additional 5,000 lives by 2014/15’, is the Cancer Drugs Fund which has been in operation since October 2010. The first of the new licensed treatments to emerge in melanoma have been made available on the Fund in certain parts of England. While NICE continues to assess the cost effectiveness of both of the new treatments, their availability on the CDF is allowing the NHS to gather real world data on their effectiveness. It will also allow clinicians to understand and manage the toxicity profile of the treatments. Time will tell if these treatments are to be recommended for more widespread use, but as more new treatments become available, we are witnessing advances that were not previously considered clinically possible.

*“I feel that if there are drugs available that could prolong the lives of melanoma patients, they should be available to those patients who would benefit...I’ve never claimed anything at all in the past; if there is a chance I can prolong my life, I’d like to be able to take whatever I can get.”<sup>7</sup> Melanoma patient*

**Expert Group Recommendation 10**

**Patients with advanced melanoma should have equitable access to all approved treatments, where clinically appropriate, in order to provide those patients with the best possible chance of long-term survival.**

The Expert Group agreed that access to new treatments must remain a priority and that patients with advanced disease should have equitable access to the full range of therapeutic options that are available and clinically appropriate. This should include newly licensed systemic therapy agents as well as surgical interventions which have been deemed to be efficacious including stereotactic surgery. Other specific surgical interventions are discussed in more detail in Chapter 4.

4 Department of Health, *Improving Outcomes: a strategy for cancer*, p.59 [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_123394.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf)

5 Professor Sir Mike Richards, 27 July 2010, [http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH\\_117970](http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_117970),

6 Melanoma Taskforce, *2015 Skin Cancer Visions* (2010), p.21

7 Parliamentary & Stakeholder Investigation: Treatment of Advanced Melanoma



## Quality Statement

Patients with advanced cutaneous melanoma should have equitable access to the full range of available clinically-appropriate therapeutic options.

## Useful Resources

- Department for Business, Innovation and Skills, *Strategy for UK Life Sciences* (2011), <http://www.bis.gov.uk/assets/biscore/innovation/docs/s/11-1429-strategy-for-uk-life-sciences>
- Department of Health, *Improving Outcomes: a strategy for cancer* [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_123394.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf)
- National Cancer Action Team, *National Cancer Peer Review Programme Report 2010-2011* [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_131669.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131669.pdf) (2011)
- National Cancer Intelligence Network (NCIN): *National collection and analysis of cancer chemotherapy* [http://www.ncin.org.uk/publications/data\\_briefings/national\\_collection\\_and\\_analysis\\_of\\_cancer\\_chemotherapy.aspx](http://www.ncin.org.uk/publications/data_briefings/national_collection_and_analysis_of_cancer_chemotherapy.aspx) (2011)
- NHS Choices Map of Medicine: *Melanoma further management* <http://healthguides.mapofmedicine.com/choices/map/melanoma3.html> (2011)
- *Parliamentary & Stakeholder Investigation: Treatment of Advanced Melanoma* [Report available on request from the Office of Pauline Latham MP] (2011)
- The Melanoma Taskforce, *2015 Skin Cancer Visions* (2010)
- The Melanoma Taskforce, *Variations in Melanoma Survey* (2011)
- UK Clinical Trials Gateway (UKCTG) <http://www.ukctg.nihr.ac.uk/default.aspx>

# Chapter 6 Survivorship and End of Life

## Group Membership

- Simon Davies Chief Executive, Teenage Cancer Trust; Chairman, Cancer52
- Catherine Wheelhouse Skin Cancer Clinical Nurse Specialist, Bradford Teaching Hospital NHS Trust; Chair, British Association of Skin Cancer Specialist Nurses

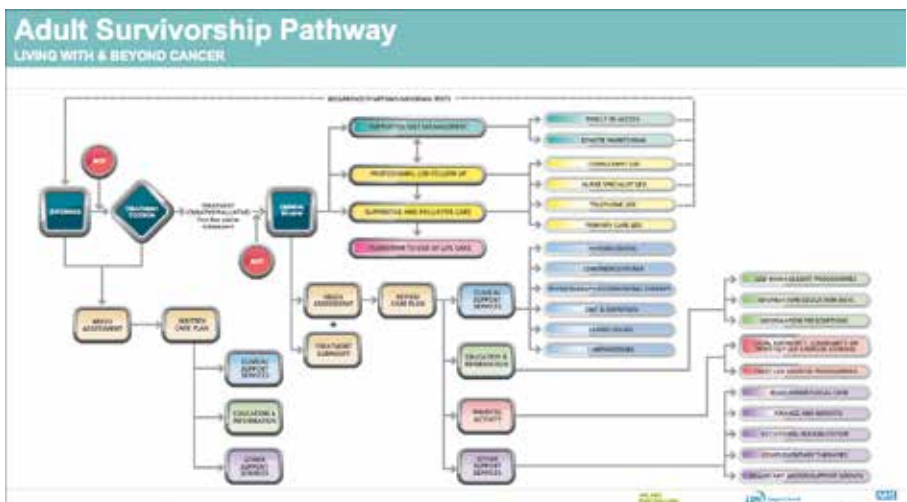
## Introduction

The Expert Group was unanimous in its belief that survivorship starts the moment the patient is told they have cancer and remains a priority for the patient well beyond discharge. The group therefore placed significant emphasis on the importance of empowering patients to self-examine and supporting them to maintain their health and psychological wellbeing throughout their diagnosis and treatment. The group also discussed the value of tailoring the pathway to the patient and the ways in which discharge could be better managed in order to meet the needs of the patient. It was clear from the discussion that the responsibility for guiding a patient through their survivorship pathway, or indeed towards palliative care, was not just that of the Skin Cancer Clinical Nurse Specialist (SCCNS) but of every health care professional involved in that patient's treatment. However, the role of the SCCNS remained central to the group's discussion and it was agreed that further work must be done to define and protect the role within the changing NHS landscape.

## Discussion

NHS Improvement has developed an Adult Survivorship Pathway which is currently being piloted at a number of test sites, tailored to the needs of four different tumour types: prostate, breast, lung and colorectal. This has been created with a view to improving quality, reducing unnecessary hospital attendances and moving the focus of post treatment care away from the disease and treatment and towards health and wellbeing.

Source: NHS Improvement





## Education and Psychosocial support

The Revised BAD Guidelines state that the three main reasons for follow-up after the treatment of primary melanoma are: to detect recurrence when further treatment can improve the prognosis; to detect further primary melanomas: and, to provide support, information and education.

### The Revised UK Guidelines for the management of cutaneous melanoma (2010) recommend that:

- Patients with in-situ melanomas do not require follow-up
- Patients with stage IA melanoma should be seen two to four times over up to 12 months to teach self-examination then discharge
- Patients with stage IB-IIIa melanoma should be seen 3-monthly for 3 years, then 6-monthly to 5 years
- Patients with stage IIIB, IIIC and resected stage IV melanoma should be seen 3-monthly for 3 years then, 6-monthly to 5 years, then annually to 10 years
- Patients with unresectable stage IV melanoma are seen according to need

Source: *British Association of Dermatologists*

The Expert Group was unanimous in its belief that clinical practice should continue to follow these guiding principles, although it was noted that a greater degree of flexibility could be applied to these principles which is discussed in more detail later on in the chapter under 'Deferred Discharge'. Members placed particular emphasis on the value of providing clear information and the appropriate psychological support to the patient at key points across the pathway. It was agreed that education and psychological support must go hand-in-hand and an appropriately trained health care professional should be able to teach the patient how to not only examine their skin and lymph nodes, but also to manage any concerns of possible recurrence.

#### Expert Group Recommendation 11

**At each follow-up appointment, whether it is with a dermatologist, plastic surgeon or CNS the patient's surgical scar, skin and lymph nodes should be examined. The patient will be asked to undress down to their underwear, removing their shoes and stockings to enable all of the patient's skin to be examined at each visit.**

*"It looks very easy when you say 'I'm going to teach my patient how to examine their skin and lymph nodes', but when you've got melanoma, every lesion feels like a little time bomb ready to go off. When you start to educate a patient the information you give them must not be to the detriment of their psychological well-being." Catherine Wheelhouse, Skin Cancer Clinical Nurse Specialist, Bradford Teaching Hospital NHS Trust*

Although health care professionals are embarking on the appropriate counselling and psychological support training, concerns were raised that funding for the necessary supervision of these Level II practitioners is being removed.



**Expert Group Recommendation 12**

In line with the National Cancer Action Team's Manual for Cancer Services: Skin Measures

**"At least one clinical core member of the team should have completed the training necessary to enable them to practice at level 2 for the psychological support of cancer patients and carers." (11-2J-103)**

**"The level 2 practitioner(s) should receive a minimum of 1 hour's clinical supervision by a level 3 or level 4 practitioners per month." (11-2J-104)**

The group recommends that SSMDTs should offer patients, their family members, partners and significant carers psychological support services in line with the service delivery of other cancer sites. This should be in line with the NICE 2004 guidance on Improving Supportive and Palliative Care Adult Cancer.

### The assessment conversation

The assessment conversation itself is a high impact intervention. It should have a therapeutic value in its own right, though it is not a therapy session. This section gives some suggestions for structuring an assessment conversation along the lines of the Calgary-Cambridge model<sup>1</sup>.

<b>Starting off</b>	It's a good idea when you start the conversation to make it clear that this is a normal, routine assessment rather than something unusual. You should explain the purpose of the meeting and describe any paperwork you are using. Make sure your patient can see what you are writing on the assessment sheet if you are using one (or a screen if you have an electronic system available) - it should be a collaborative exercise and it is entirely up to the patient what is subsequently done as a result of your conversation.
<b>Managing the assessment</b>	Take time to talk about things more generally ("how have you been managing with the treatment?..." before expecting the patient to reveal more personal details. Concentrate on building a rapport and gaining their trust. When discussing a concern move from the general to the specific. "You've put down insomnia. Can you tell me a bit more about that? What does your sleep pattern generally look like?... Okay, so what's happening when you find yourself awake during the night?..." Emphasise the patient's own resources in managing their difficulties. "What do you think that's about?... What do you think might be helpful in improving your sleeping?... Acknowledge achievements and build on things that are going well. Make it solution-focused rather than becoming bogged down with the problem itself. "Staff we focus on now to what we might be able to do about this problem?" "What would be one thing that could be done to improve matters even slightly?" Focus in on the main concerns - don't attempt to find solutions to everything. If a patient has lots of concerns do acknowledge them and don't try to skip over some but do be firm about the amount of time you have available. "I see you have identified a lot of concerns. We only have a x minutes of time available today; which of these would you like to focus on today?"
<b>Wrapping up</b>	Summarise what you have discussed and what steps, if any, you will take (e.g. referral) and those that the patient has agreed to take. Record what you have agreed to do in a care (or action) plan (note about this later). If a referral is to be made, be sure that you have obtained the patient's permission for this to go ahead. Thank the patient and ask them if they are comfortable with the summary sheet being placed in their medical case notes or kept on the computer system. Offer them a copy of the summary sheet or assessment tool if you have used one and the care plan.  Do bear in mind that it is not the aim to try to solve all your patient's problems there and then. For example, if someone confides in you that they are living in poor housing conditions there may be little you can do about that (though you might be able to offer, with their permission, an onward referral to other services). But the very fact that you have listened and heard their story will release some of the person's anxieties ("they now know what I have to deal with") and help you to understand what they have to cope with ("I now know what that person is facing").

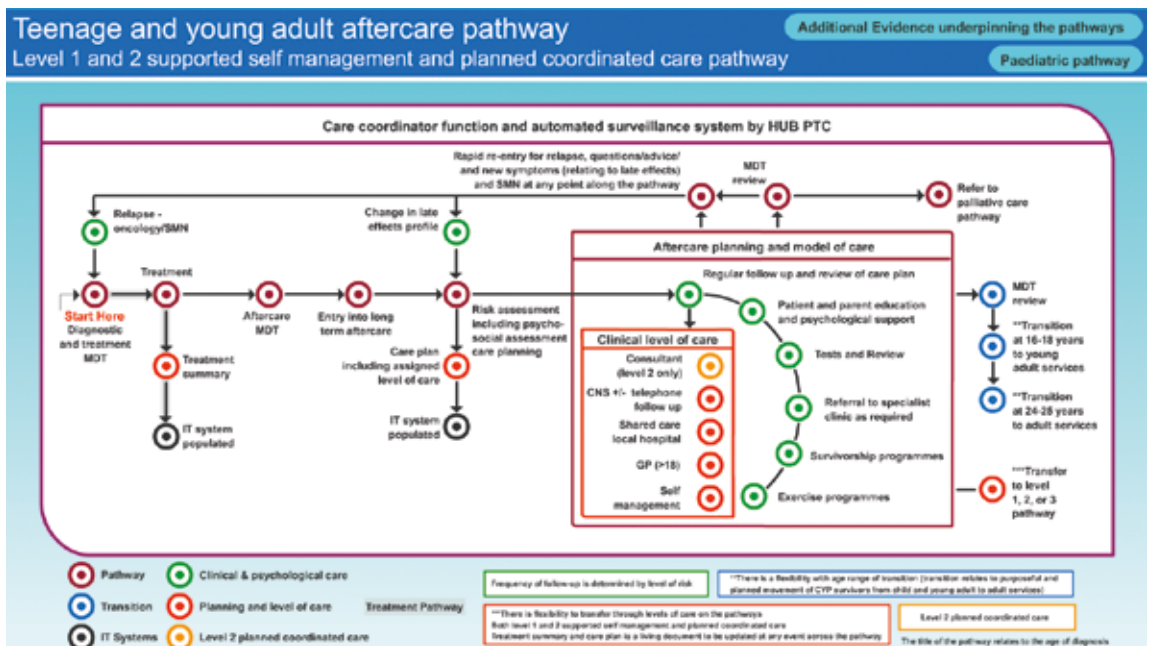
The group agreed that education is a critical part of the pathway and that the importance of self-examination must be impressed upon the patient. The members felt that it would also be easy to audit this process, recording when the information was given to the patient and the name of the health care professional who facilitated the training.

When measuring and auditing the delivery of a psychological assessment, the group agreed that the Holistic Needs Assessment is a measurable intervention.

The Holistic Needs Assessment considers all aspects of a person's needs. It will identify people who need help; provide an opportunity for the person to think through their needs and make a plan about how best to meet these; help people to self manage their melanoma; and help the Skin Cancer team to target their support and care efforts.<sup>1</sup>

The National Cancer Survivorship Initiative's Children and Young People's working group has developed an online interactive pathway which can be accessed by any young patient. This is a good example of a 'survivorship' pathway.

Source: National Cancer Action Team (2011)



Source: NHS Improvement

1 National Cancer Action Team, Holistic Needs Assessment for people with cancer: a practical guide for healthcare professionals (2011), p. 5





## Skin Cancer Clinical Nurse Specialists

The group identified a lack of clarity over the role of the Skin Cancer Clinical Nurse Specialists (SCCNS), particularly as they tend to fulfil many roles across the pathway. The role of SCCNS and their workload are issues that have been consistently raised by the Melanoma Taskforce. In the Taskforce's *2015 Skin Cancer Visions* report, members recommended that a strategic review of the nursing workforce be undertaken to ensure that the division of labour between doctors and nurses is clarified so that both can be deployed more effectively. <sup>2</sup> The Expert Group identified this as an ongoing challenge for the NHS.

In order to bring some clarity to the role of specialist nurses, the group was keen to identify and emphasise those points in the pathway where they play a particularly critical role.

### Expert Group Recommendation 13

**Patients should have access to the SCCNS from the Breaking Bad News Consultation (BBNC) onwards. Following the BBNC, the patient should be: given time with SCCNS to further discuss their treatment options and plans; given relevant information in accordance with the treatment plan; directed to further information that they can access in their own time; given contact numbers; allocated a Key Worker; and be given a holistic assessment by the SCCNS or Key Worker.**

The group agreed that at the first follow-up appointment following definitive surgery, patients should be offered an appointment with the SCCNS. If the patient accepts, the appointment should take place before the patient's second follow-up appointment. Patients should be encouraged to be accompanied at their consultation; the consultation will cover self-examination of skin and lymph nodes and it will therefore be useful to bring someone who will be in a position to examine the patient's back when at home.

The group was keen to emphasise the time that should be allocated to an SCCNS consultation. It was agreed that it should be delivered in an unhurried, friendly environment, taking into account the patient's holistic and psychological well-being. One hour should be factored into the delivery of these consultations, with an additional half hour for paperwork (CNS notes; letter to GP; and local electronic systems). This should be part of the work plan agreed between the specialist nurse and their individual MDT and PCT.



#### Quality Statement

People having treatment for melanoma are offered timely and personalised information and support including an appropriately-tailored written follow up care plan.

It was acknowledged that in light of the fact that the nursing workforce is currently at capacity, the Key Worker allocated to the patient with melanoma may not always be an SCCNS and could be an alternative member of the skin cancer multi-disciplinary team.



#### Quality Statement

People with melanoma have access to a named Key Worker who will be a SCCNS, (but may be an alternative named member of the Skin Cancer MDT), and are offered a holistic needs assessment, including psychological support requirements, at each key stage of care.

## Deferred Discharge

The group recognised the flexibility included in the BAD Guidelines that allows clinicians to manage the period of follow-up care and the discharge of patients



with melanoma. However, members felt that the guidance could go further and enable clinicians to manage a deferred discharge for appropriate patients. Following the patient's second Out-Patient Department (OPD) appointment and a SCCNS consultation, they can be offered Deferred Discharge (DD) (subject to the stage of disease and clinical circumstances). During the period of DD the patient will not have a routine follow-up appointment in secondary care. If the patient displays symptoms that cause them concern during this period of DD, they will have direct access back to their Skin Cancer Service or SSMDT.

Members suggested that some patients would be happy to attend fewer follow-up clinics if: they had sufficient knowledge to carry out self-examination of their skin and lymph nodes; were equipped with the necessary preventative measures to avoid recurrence; and had access back into specialist care without a GP referral. At the same time, it was identified that some patients find self-examination of the nodes to be a stressful process and can therefore struggle with discharge. These patients would welcome the sense of security that comes with knowing they can access specialist care at any time as opposed to being taken out of the system altogether.



#### Quality Statement

Melanoma patients with good prognosis melanoma (AJCC stage 0 to 1A), who have had a second out-patient department (OPD) appointment and SCCNS consultation following definitive surgery, may be offered Deferred Discharge to allow rapid access back to their Skin Cancer Service if they display symptoms that are cause for concern.

### Follow up

For the various stages of melanoma, different follow-up protocols apply. In current clinical practice, patients with Stage 0 melanoma are discharged back into primary care and are offered a SCCNS consultation following a Wide Local Excision out-patient department appointment. Patients with Stage 1A melanoma are seen two or four times over a period of up to 12 months in order to teach self-examination. Members of the group felt that patients could be offered deferred discharge at an earlier stage than the revised BAD Guidelines currently recommend; as such the group agreed that quality care should include an opportunity for deferred discharge to be discussed with patients with Stage 1B to Stage IV.



#### Quality Statement

Patients (AJCC stage 1B to IV) will have regular specialist follow up, 3 monthly for 3 years, thereafter 6 monthly for 2 years, which can include protocol-led clinical nurse specialist follow-up. After the 5 year period of specialist follow-up, Deferred Discharge is discussed with the patient.

### End of Life

The Department of Health has acknowledged that palliative care does not work as well as it should in all areas of the country, with evidence of significant variation in access to the appropriate service. A new system of palliative care funding is due to be in place by 2015, with eight sites currently undertaking pilots. However, the group did not dispute existing guidance and highlighted the fact that there is a plethora of guidance currently available on End of Life Care.

This includes *The route to success in end of life care - achieving quality in acute hospitals* (2010) which was designed to re-shape how staff work with each other, their patients, their community and their social care partners to improve care quality. This over-arching framework is supported by the recently published *Transforming*



*end of life care in acute hospitals; the route to success 'how to' guide* (2012). They also signposted NICE guidance, *Improving Supportive and Palliative Care for Adult Cancer* (2004), and the most recent guidance in the form of the NICE Quality Standard for *End of Life Care in Adults* (2011).

The group did suggest that there should be a nominated, named individual or clinical team that provides palliative care services to melanoma patients. This should be part of their job description or the Service Level Agreement.



### Quality Statement

Patients with melanoma have access to all appropriate palliative interventions delivered by an expert nominated clinical team.

### Expert Group Recommendation 14

All MDTs should have a defined referral pathway to a nominated clinical team for patients requiring palliative care input.

## Evidence Sources

- British Association of Dermatologists, *Revised UK guidelines for the management of cutaneous melanoma* [http://www.bad.org.uk/Portals/\\_Bad/Guidelines/Clinical%20Guidelines/Melanoma%20guidelines%202010.pdf](http://www.bad.org.uk/Portals/_Bad/Guidelines/Clinical%20Guidelines/Melanoma%20guidelines%202010.pdf) (2010)
- National Cancer Action Team, *Holistic Needs Assessment for people with cancer: a practical guide for healthcare professionals* <http://www.ncat.nhs.uk/our-work/living-with-beyond-cancer/holistic-needs-assessment> (2011)
- National Cancer Action Team, *National Cancer Peer Review Programme: Manual for Cancer Services, Version 2.0* (2011)
- National Cancer Patient Experience Survey 2011/12 <http://www.quality-health.co.uk/surveys/2011-12-cancer-survey.html> (2011)
- National Cancer Survivorship Initiative, *Assessment and Care Planning* <http://www.ncsi.org.uk/wp-content/uploads/Assessment-and-Care-Planning-Workstream-Report.pdf> (2010)
- NHS Improvement, *Adult Survivorship Pathway* [http://www.improvement.nhs.uk/cancer/survivorship/adult\\_survivorship\\_pathway/](http://www.improvement.nhs.uk/cancer/survivorship/adult_survivorship_pathway/)
- NHS Improvement, *Teenage and Young adult aftercare pathway* <http://www.improvement.nhs.uk/cancer/SurvivorshipLivingWithandBeyondCancer/TeenageandAdultAftercarePathway/tabid/336/Default.aspx>
- NHS Improvement, *Testing pathways of care for those living with and beyond cancer* <http://system.improvement.nhs.uk/ImprovementSystem/ViewDocument.aspx?path=Cancer%2fNational%2fWebsite%2fNCIS%20Prototype%20site%20info%20to%20support%20EOI.pdf> (2012)
- NHS Choices Map of Medicine, *End of life care in adults assessment and care planning* [http://healthguides.mapofmedicine.com/choices/map/end\\_of\\_life\\_care\\_in\\_adults1.html](http://healthguides.mapofmedicine.com/choices/map/end_of_life_care_in_adults1.html) (2011)
- NICE Quality Standard, *End of life care for adults* <http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp> (2011)
- The Melanoma Taskforce, *2015 Skin Cancer Visions* (2010)



# Chapter 7 Service Design & Implementation

## Overview

The 2012 Health and Social Care Act sets out the Government's vision to modernise the NHS. It is the Government's stated intention that the reformed NHS is to be 'patient-led', with patient access to information and choice the key driver used to improve health and wellbeing outcomes. In particular, the way in which services are commissioned is to be completely transformed. Health care professionals at the local level will have a greater degree of autonomy and accountability and will lead service design and the commissioning of the majority of services via Clinical Commissioning Groups (CCGs).

This new landscape presents multiple opportunities to review the way in which melanoma services are designed, accessed and delivered in the NHS and any reformed melanoma pathway will have to take this new landscape into account. The Expert Group has therefore given consideration to the way in which the recommendations and quality statements proposed in this report might be implemented within this reformed NHS structure.

## Service Design

### Data Collection

Following the publication of the White Paper, *Equity and Excellence: Liberating the NHS*, the Government consulted on its proposals to revise the way in which information in the NHS is accessed, collected, analysed, and utilised. *Liberating the NHS: an Information Revolution* proposed to transform data collection and access so as to enable greater patient choice and to inform service design with the ultimate aim of improving patient outcomes. The proposals place significant emphasis on the role of health care professionals in the development of data solutions that will drive an improvement in outcomes:

*"In order to achieve the benefits of the information revolution, clinicians and other care professionals need to continue to play an active role in developing information solutions that are safe, that work for patients and service users and that help improve outcomes. The new approaches need to be based on clinically governed standards and accurate recording of data. NHS and adult social care services have a vast amount of data flowing through them, but much of it does little to inform those who provide and use services about the things that matter to them."*  
*Liberating the NHS: an Information Revolution, Department of Health (2011)*

The group believes that effective data collection in melanoma is central to informing patients to aid patient choice, and supporting commissioners in the development of services. Indeed, *Improving Outcomes: a Strategy for Cancer* places considerable emphasis on improving data collection systems in order to gather the appropriate

1 Department of Health, *Liberating the NHS: an Information Revolution* (2011), p.35



## South West Public Health Observatory (SWPHO)

The South West Public Health Observatory hosts the South West Cancer Registry undertaking its statutory function of recording all cancers in the South West, Hampshire and Isle of Wight. It participates in national, regional and local projects. SWPHO has a long history of collaborative work with clinicians at regional level and specifically with Skin Specialists undertaking a large amount of Clinical Audits on their behalf.



In recent years it has become the lead cancer registry for Skin Cancer in England. It provides intelligence support for the National Cancer Intelligence Network Skin Cancer Site Specific Clinical Reference Group and responds to requests from the Department of Health, clinicians, researchers and members of the public. SWPHO has provided expert guidance to many public bodies including NICE, COMARE and SunSmart. In 2009 it launched the online Skin Cancer Hub, designed to help inform and support professionals and the public about skin cancer prevention and early diagnosis.

information that will in turn inform decisions about service design and delivery.<sup>2</sup> *Liberating the NHS: an Information Revolution* also states that “in order to grasp the opportunities offered by the information revolution, clinicians and care professionals need to be able to access the best evidence of outcomes, interventions and risks. Evidence needs to be user-friendly, up-to-date and available at the point of care, to inform discussions with patients and service users.”<sup>3</sup> The group suggested that whilst some data collection systems are in place within the melanoma pathway, there are still key elements of the pathway, particularly in surgery, that are not currently mined for valuable data.

The post-surgical data sets that were discussed by the group included:

- Re-admission rates;
- Resection rates;
- Mortality rates (30 day);
- Morbidity rates;
- Complication rates;
- Sentinel Lymph Node Biopsy procedure rates;
- Sentinel Lymph Node Biopsy positioning; and
- Patient Reported Outcomes.

It was agreed that morbidity rates and complication rates in post-surgical melanoma patients should be collected. The other data sets listed are currently collected in some form, but it was made clear that the way in which the data is collated is not always effective. Dr Veronique Poirier from the South West Public Health Observatory (SWPHO) noted that for example, the lack of standardised usage of OPCS codes for data collection on SLNB across the NHS hinders the ability of analysts to make useful and accurate comparisons.

*“One of the important things is to get a better agreement on the type of coding used. This would make it easier to utilise Hospital Episodes Statistics (HES) and Cancer Registry data more effectively to monitor outcomes at a national level.”*  
*Dr Veronique Poirier, South West Public Health Observatory*

### Expert Group Recommendation 15

**Appropriate data collection systems should be put in place to collate, publish and audit post-surgery morbidity and complication rates.**

### Expert Group Recommendation 16

**Standardised coding in data collection should be put in place to allow for accurate comparisons to be made between networks at both the local and national level.**

The group signposted the work of Dr Katherine Acland on behalf of the Melanoma Study Group and Mr Howard Peach on behalf of the British Association of Plastic, Reconstructive and Aesthetic Surgeons, both of whom are looking at data collection systems in melanoma care. The National Cancer Intelligence Network (NCIN) is currently developing the Cancer Outcomes and Services Dataset (COSD) which will replace the current National Cancer Dataset and will include the Cancer

<sup>2</sup> Department of Health, *Improving Outcomes: a strategy for cancer* (2011)

<sup>3</sup> Department of Health, *Liberating the NHS: an Information Revolution* (2011), p.36





Registration dataset and additional site specific data items relevant to the different tumour types.

## Integration of care

As part of the Government's drive to improve patient choice, measures have been introduced to extend the choice of providers available to commissioners. By extending the range of Any Qualified Provider (AQP) available to patients, the Government expects to be able to drive up quality, empower patients and enable innovation. The Department of Health has also stated that by extending the choice of provider it hopes to improve access, address gaps and inequalities in service delivery, and improve the quality of services where patients have identified variable quality in the past. However, these proposals have been met with some public and professional trepidation, with concerns voiced around the risks of 'privatisation' and 'cherry picking' by private providers.

Indeed, concerns were raised by members at numerous points across the pathway discussion on the role of private providers in the delivery of melanoma care services. The group was adamant that integration must remain the guiding principle in the provision of melanoma care if private providers are to deliver services alongside NHS providers. It was also made clear that patient information must be shared across the pathway by all providers and that decisions are made with all the necessary clinicians involved, be they in the private or public sector.

### Expert Group Recommendation 17

**The provision of melanoma care must be delivered via an integrated system, irrespective of the provider. Private and public sector providers must be able to communicate effectively and ensure that decisions on the patient's care pathway are made with all of the necessary members of the clinical team involved.**

## Role of Clinical Commissioning Groups

The commissioning of services at the local level will be led by Clinical Commissioning Groups (CCGs). They will be responsible for the commissioning of all secondary and community care services and crucially will have responsibility for the management of care and resources. With the rising incidence of melanoma in England, the demand for specialist skin cancer services will increase and resources, including workforce capacity, will have to be managed accordingly. As such, the group looked at the ways in which commissioning bodies within the new NHS could be mandated to manage the professional capacity and expertise available within their commissioning area. The group agreed that Clinical Commissioning Groups in particular have a key role to play in not only monitoring the quality of melanoma service provision and the level of integration within their commissioning area, but also the capacity of the workforce to deliver a high standard of melanoma care.

### Expert Group Recommendation 18

**Clinical Commissioning Groups should manage the workforce capacity in accordance with the increasing demand for specialist skin cancer services to ensure that patients within their commissioning area have equitable access to high quality melanoma care.**



### National implementation: NHS Commissioning Board

The new NHS Commissioning Board (NHSCB) has been tasked with delivering the improved patient outcomes that are at the heart of the Government's health strategy. From April 2013, the NHSCB will oversee the national commissioning budget; develop and manage the system of CCGs; promote equitable access and integrated care delivery; and commission specialised services. Perhaps most importantly, it has also been set the task of developing guidance to support commissioners to provide high quality care. The core principles of the Expert Group's proposals are intended to inform the development of this commissioning guidance, and the way in which melanoma services are designed and delivered at the local level.

#### Expert Group Recommendation 19

**The NHS Commissioning Board should develop commissioning guidance for the provision of melanoma services to secure equitable access to high quality, specialised, melanoma care across the country.**

To support the delivery of high quality melanoma care in England, the swift publication of a NICE Quality Standard for Skin Cancer (including melanoma) is pivotal. NICE Quality Standards are central to the Government's vision for an outcomes-focused NHS and will act as a key driver in achieving improvements in the quality of melanoma care in England and equity of access to a high standard of services. The quality statements presented in this report have been written as 'aspirational, but achievable, markers of high-quality, cost-effective patient care', so as to be in line with NICE's own definition of a quality statement. The Expert Group hopes that its quality statements, and supporting recommendations, will prove to be a useful resource for NICE as it develops the forthcoming Quality Standard in Skin Cancer.

In the process of carrying out this critical examination of the melanoma pathway and existing melanoma guidance, it was also made clear that a review of the NICE Improving outcomes for people with skin tumours (including melanoma), first published in 2006, would be beneficial.

#### Expert Group Recommendation 20

**The group recommends the swift publication of the NICE Quality Standard for Skin Cancer (including melanoma) and that NICE guidance Improving outcomes for people with skin tumours (including melanoma) (2006/2010) is updated in accordance with the newly published Quality Standard.**

### Local implementation: Strategic Clinical Networks

Members of the group saw Cancer Networks as having a pivotal role to play in the improvement of melanoma care. To date, cancer networks have been successful in improving the quality of care across integrated pathways, and the Department of Health has provisionally committed to funding cancer networks to the end of the 2012/13 financial year. A review of Clinical Networks is currently underway and it appears likely that in the new NHS, Cancer Networks will be maintained as part of the emerging system of Strategic Clinical Networks (SCNs). These Networks will be in place to support commissioners to improve the quality of service provision and patient outcomes within a specific clinical area. The NHSCB will hold the SCNs to account and will be responsible for the allocation of budgets.



As the Networks develop, their mandate may narrow to allow for a more targeted focus on particular tumour types. In order to manage the integration of the complex melanoma pathway and the rising incidence rates of melanoma, the group recommends that the NHSCB considers establishing a melanoma lead within each clinical network to provide the necessary leadership and expertise at the local level. The quality statements and recommendations presented in this report will be a valuable resource for the emerging clinical networks and should be appropriately shared.

**Expert Group Recommendation 21**

**The NHS Commissioning Board should consider the level of specialism within the strategic clinical cancer networks, as well as the value of establishing a melanoma lead at the local level in order to provide the necessary leadership and guidance in the development of this complex pathway.**



## Glossary of Terms

### Adjuvant therapy

A term used to describe additional treatments, such as chemotherapy or radiotherapy, given after cancer surgery.

### Any Qualified Provider (AQP)

As part of the Government's drive to improve patient choice, measures have been introduced to extend the choice of providers available to commissioners. By broadening the range of Any Qualified Provider (AQP) available to patients, the Government expects to be able to drive up quality, empower patients and enable innovation.

### 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 Drugs Fund (CDF)

The CDF was established in full in April 2011, with a total budget of £200million being made available nationally each year until the end of the 2013/2014 financial year to fund cancer treatments not currently available on the NHS. The process is administered locally by Strategic Health Authorities (SHAs), but with each following the same central guidelines.

### 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. The Government has confirmed the funding of cancer networks to the end of the 2012/13 financial year and will set out their place in the reformed NHS in the coming months.

### Cancer Reform Strategy (CRS)

First published in 2007, and under the direction of National Clinical Director for Cancer, Professor Sir Mike Richards, the CRS was 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 Coalition Government announced a review of the policy in 2010 and it has since been superseded by Improving Outcomes: A Strategy for Cancer, which was published in January 2011.

### Clinical Commissioning Groups (CCGs)

The commissioning of services at the local level will be led by Clinical Commissioning Groups (CCGs). They will be responsible for the commissioning of all secondary and community care services and crucially will have responsibility for the management of care and resources.

### Enhanced Recovery Programme (ERP)

The Enhanced Recovery Programme (ERP) is a Quality and Improvement Tool designed by the NHS Institute for Innovation and Improvement. Originally known as the multi-modal approach, it is also known as 'fast-track surgery'. It is designed to reduce the length of time the patient is in hospital; increase the number of patients treated (if there is the demand) or reduce the level of resources if necessary; and to create a better staffing environment.

### Epiluminescence Microscopy

Epiluminescence microscopy is a non-invasive technique that, by use of oil (or gel) immersion, makes sub-surface structures of skin accessible for in vivo microscopic examination and thus provides additional criteria for the diagnosis of pigmented lesions.

### European Organisation for Research and Treatment of Cancer (EORTC)

The aims of the European Organisation for Research and Treatment of Cancer (EORTC) are to develop, conduct, coordinate, and stimulate translational and clinical research in Europe to improve the management of cancer and related problems by increasing survival but also patient quality of life. The ultimate goal of the EORTC is to improve the standard of cancer treatment through the testing of more effective therapeutic strategies based on drugs, surgery and/or radiotherapy that are already in use and also through the development of new drugs and other innovative approaches. This is accomplished mainly by conducting large, multicenter, prospective, randomized, phase III clinical trials. In this way, the EORTC facilitates the passage of experimental discoveries into state of the art treatments.

### GPs with a Special Interest (GPwSI)

GPwSIs are GPs that supplement their generalist role by delivering a clinical service beyond the normal scope of general practice.

### 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.



## Improving Outcomes: a strategy for cancer

In January 2011, the Department of Health published its strategy for cancer. It sets out how the Coalition Government plans to tackle the preventable causes of cancer and to encourage early diagnosis; describes the ways in which patient choice is to be extended throughout the health and social care systems; and identifies gaps in information on health outcomes. This strategy supersedes the previous Government's Cancer Reform Strategy (CRS).

### Isolated Limb Infusion (ILI)

Isolated limb infusion (ILI) is a form of regional chemotherapy. This is a way of having high dose chemotherapy just into one arm or leg, without the drugs circulating through the rest of the body. It is only used if the melanoma has come back in the same limb in which it started and if it cannot be safely and effectively removed by surgery. Fine tubes are inserted in the limb blood vessels, the limb is then cut off from the rest of the body using a tourniquet, and a very high dose of chemotherapy is administered to the limb. This is safe because the drugs stay in the limb- they cannot affect the rest of the body.

### Isolated Limb Perfusion (ILP)

Isolated Limb Perfusion (ILP) is similar in principal to ILI (above); however, it is a bigger operation because the surgeon puts tubes into the blood vessels that carry blood in and out of the limb. The blood supply to the limb is cut off from the rest of the circulation and the blood is provided with oxygen using a heart-lung machine. This allows for longer periods of exposure to chemotherapy, and stronger mixtures of drugs to be used.

### Key Worker (KW)

The Key Worker is a person who, with the patient's consent and agreement, takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice.

### Lesion

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

### Local Hospital Skin Cancer Multidisciplinary Team (LSMDT)

Local Hospital Skin Cancer Multidisciplinary Teams (LSMDT) are usually based in cancer units in district general hospitals. The LSMDT is a team of health professionals who work together to decide on the best way to manage a patient's care. In Melanoma the LSMDT can include many different health professionals including dermatologists, surgeons (including plastic (reconstructive) surgeons), oncologists, radiologists, specialist nurses, GPs with a special interest in skin cancer, physiotherapists, psychologists, lymphoedema services, occupational therapists, cosmetic camouflage advisers and histopathologists.

### Malignant melanoma

Melanoma is a cancer of the skin. 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 11,000 people are diagnosed with malignant melanoma every year. There are many types of melanoma, with the following three types making up around 90% of all diagnosed cases:

- Superficial spreading melanomas are most common in middle aged people and will tend to grow outwards rather than

downwards into the skin. The melanoma is not usually at risk of spreading to other parts of the body until it begins to grow downwards into the deeper layers of skin and beyond.

- Nodular which tends to develop quite quickly and is most often found on the chest or back. It begins to grow downwards, deeper into the skin, quite quickly if it is not removed.
- Lentigo maligna develops from very slow growing pigmented areas of skin called lentigo maligna or Hutchinson's melanotic freckle. Lentigo maligna and lentigo maligna melanoma are most common in elderly people and are most common on the face. The lentigo maligna is flat and grows outwards in the surface layers of the skin. So it may gradually get bigger over several years and may change shape. If it becomes a lentigo maligna melanoma, it starts to grow down into the deeper layers of the skin and may form lumps (nodules).

### Morbidity

The relative incidence of a particular disease in a specific locality.

### 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 Government's cancer strategy. It works closely alongside the Cancer Policy Team in the Department of Health and with 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 Government's drive to improve cancer outcomes.

### NHS Commissioning Board (NHSCB)

From April 2013 the NHS Commissioning Board (NHSCB) will lead on the achievement of health outcomes; allocate and account for NHS resources; lead on quality improvement; and promote patient involvement and choice. The NHSCB will develop and manage the system of CCGs and will have an explicit duty to promote equality and tackle inequalities in access to healthcare.

### NICE

The National Institute for 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. Under the Health and Social Care Act (2012), NICE will become a non departmental public body and, with social care added to its remit, will be renamed the National Institute of Health and Care Excellence.





## 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.

## Service Level Agreements (SLAs)

A Service Level Agreement (SLA) is reached between PCTs and service providers and describes the key services that will be provided and the quality standards that have been agreed in terms of service delivery. A typical SLA will set out: the service that is being provided; the standards of service expected and the timetable for delivery; respective responsibilities of the provider and PCT; provisions for legal and regulatory compliance; mechanisms for monitoring and reporting of service; payment terms; how disputes will be resolved; confidentiality and non-disclosure provisions; and termination conditions. An SLA allows for a common understanding of the priorities and responsibilities of all parties and has built-in key performance indicators (KPIs).

## Sentinel Lymph Node Biopsy

Sentinel lymph node biopsy (SLNB) 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 Clinical Nurse Specialist (SCNS)

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)

## 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. In 2010, the Melanoma Taskforce published a report that made recommendations for 2015 Visions in skin cancer prevention and treatment. [Available on request from the Melanoma Taskforce Secretariat on 020 7824 1850]

## Specialist Skin Cancer Multi-disciplinary Team (SSMDT)

Specialist Skin Cancer Multi-disciplinary teams (SSMDTs) are generally located in larger hospitals that have cancer centres, or plastic surgery centres. The SSMDT is a team of health professionals who work together to decide on the best way to manage a patient's care. In Melanoma the SSMDT can include many different health professionals including dermatologists, surgeons (including plastic (reconstructive) surgeons), oncologists, radiologists, specialist nurses, GPs with a special interest in skin cancer, physiotherapists, psychologists, lymphoedema services, occupational therapists, cosmetic camouflage advisers and histopathologists.

## Stereotactic radio-surgery

Stereotactic radio-surgery delivers a very precise dose of radiation. Stereotactic means locating a point (in this case the position of the tumour in the brain) using three-dimensional coordinates. Stereotactic radio-surgery ensures that the maximum amount of radiation is aimed at the tumour and that surrounding tissue is not exposed. It may be given as a single dose or delivered over several sessions. Stereotactic radio-surgery is performed under local anaesthetic, but the scalp is numbed. A lightweight frame is attached to the scalp, and a series of scans accurately pinpoint the position of the tumour.

## 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.

## Teledermatology

Teledermatology refers to the use of digital images, together with relevant patient information, as a means of aiding referral of patients with skin problems from primary to secondary care.

## Urgent Suspected Cancer Framework (USC)

NICE Guidance (Referral for suspected cancer (CG27)) states that if a patient's condition is deemed to be 'urgent' then the patient must be seen within the national target for urgent referrals which is currently two weeks.



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# Quality in Melanoma Care:

A best practice pathway



The Melanoma Taskforce

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