

# *'Variations in Melanoma Survey'*



The Melanoma Taskforce

Chaired by Siân James MP





## Melanoma Taskforce

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## Melanoma Taskforce

### MELANOMA TASKFORCE MEETING 22<sup>nd</sup> NOVEMBER 2011, HOUSE OF COMMONS DISCUSSION REPORT

#### OVERVIEW

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The Melanoma Taskforce convened in Westminster on Tuesday 22<sup>nd</sup> November to discuss plans for 2012 activity. Chaired by Stephen Gilbert MP, in place of Taskforce Chair Siân James MP who was unable to attend, the meeting was an opportunity for the Taskforce to review the success of 2011 activity, in particular the publication of the Skin Cancer Visions report and the launch of the Mole & Skin Check Guidelines for Health & Wellbeing Professionals, and to agree the Melanoma Taskforce priorities for 2012.

The Taskforce was presented with the results of its research survey that sought to look at the melanoma treatment pathway and explore variations in melanoma care. The group also heard from the South West Public Health Observatory (SWPHO), which leads nationally on the collection of melanoma statistics, and discussed findings which indicated geographical variation in both incidence and mortality from melanoma.

#### RECOMMENDED NEXT STEPS

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Following a group discussion on the potential causes of variation and current perceived weaknesses in the melanoma care pathway, it was agreed that a sub-group of the Taskforce be established to undertake further research in this area. The sub-group will look specifically at developing recommendations and guidance to support commissioners and clinicians alike to deliver quality standards of care across the melanoma pathway in the NHS.



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### DISCUSSION

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The following discussion was based on the main findings of the Taskforce survey (the results of which are contained in Appendix I) and the data presented by Veronique Poirier of the SWPHO, on the high levels of variation in melanoma incidence and mortality rates across England. The group identified a number of areas of concern including: public awareness; GP education; referral from primary care; teledermatology; the role of Cancer Nurse Specialists (CNS); peer review and audit; undergraduate medical curricula; and Sentinel Node Biopsy (SNB) and the increasing importance of staging disease.

#### **Public Awareness**

Critical to the improvement of melanoma incidence and mortality rates is greater public understanding of prevention, detection and treatment. Men, children and young people were all identified as key targets for any public awareness raising programme.

#### **GP Education**

Following an update from Cancer Research UK on its work with the British Association of Dermatologists (BAD) on the development of a GP education tool, the group discussed the role that primary care practitioners must play in the melanoma pathway. The group reached a consensus that better information and training should be available for GPs to aid them in their diagnosis and referral of suspected melanoma. For example, there should be at least one GP in every practice who can use a dermatoscope and identify skin lesions.

It was agreed that there are serious problems within primary care of misdiagnosed or delayed diagnosis and the cost of litigation to the NHS as a result of misdiagnosed melanomas is of real concern.

***ACTION POINT: Stephen Gilbert MP to table Parliamentary Questions asking the Secretary of State for Health the scale and number of claims put before the NHS Litigation Authority relating to misdiagnosed melanomas.***

#### **Appropriate referral from Primary Care**

Managing the interface between primary and secondary care was considered by the group to be of particular importance. Ensuring that GPs make timely and appropriate referrals into secondary care is integral to GP education and training, as above. In managing this interface, it is important that channels of communication are open and multi-directional. It was noted that where a GP has expertise in melanoma, skin cancer or dermatology, this is flagged with primary and secondary care colleagues. The potential for triaging and referral refinement services by suitably qualified GPs was also discussed although there was no consensus on whether this should be recommended as a solution, considering the potential waiting times to be triaged could often be longer than the 2 week urgent cancer referral currently in place.

#### **Teledermatology**

It was agreed that teledermatology should be more widely used in the NHS. Concerns were raised that these services are increasingly being provided by the private sector in isolation of any clinical assessment or liaison with NHS services.



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### **Cancer Nurse Specialists**

The role of Clinical Nurse Specialists (CNS) in melanoma was an area of particular concern for the group. The results of the Taskforce survey were mirrored by the reported experiences of attendees. Whilst it was agreed that resources are not always readily available to employ CNSs, problems do arise when a trust is in a position to commission CNS services and they find there is a general 'paucity' of nurses with the necessary skills.

Concerns were also raised by the group that the workload of CNSs continues to grow and that their unique skill set is often not utilised appropriately, with many nurses being called away from their specialist work and onto the wards for general practice. The CNSs that were in attendance also suggested that there is a lack of understanding of their role and value, particularly amongst the higher echelons of Trust management.

Anecdotal evidence, reported to the group by individual attendees, suggests that some CNSs are working across two tumour groups at any one time, often covering five Acute Trusts in one week. This is an area where the group was particularly keen to see further action taken.

***ACTION POINT: Stephen Gilbert MP to table a Parliamentary Question asking the Secretary of State for Health how the role of CNSs can be enhanced in order to tackle variations in standards of care in melanoma.***

Within the discussion on CNSs, the issue of psychological support services was also raised. The survey showed that only half of Trusts or Networks are routinely offering patients psychological support throughout the melanoma pathway. The group agreed that, in practice, it is the CNS that is expected to deliver these services. Whilst some are trained to assess the psychological state and wellbeing of their patients, they are not always able to refer the patient on to the appropriate care. Furthermore, it was agreed that there are not enough CNSs with the necessary skill set, and as such the services are not always readily available.

***ACTION POINT: Stephen Gilbert MP to table a Parliamentary Question asking the Secretary of State for Health on the level and quality of psychological support service provision in the melanoma cancer pathway.***

### **Peer Review & Audit**

In response to the significant variation in the number of Acute Trusts and Cancer Networks that carry out regular audits of the melanoma pathway, the group agreed that it is reasonable to expect some local variation. In certain instances, where the clinician is confident that a particular pathway is working well, an audit is not considered necessary.

It was noted by the group that in the daily or weekly process of reviewing each patient at Multi-Disciplinary Team (MDT) meetings, the consultant is effectively carrying out an audit. By engaging with MDTs on a case-by-case basis, any variance or deviance from the agreed and approved melanoma pathway will become apparent, and can be duly rectified.



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It was noted by the group that the audit process is closely linked with Peer Review. Each Cancer Network should have an approved melanoma pathway which is then regularly subjected to Peer Review. However, the group said it would be difficult to prove whether local acute trusts were directly following a cancer network's published pathway.

The group believed that the National Cancer Intelligence Network (NCIN) could usefully look at whether the peer review process could be improved with regard to how it assesses adherence to the melanoma patient pathway to avoid variation, particularly at the acute trust level.

### **Undergraduate Medical Curriculum**

The group agreed that undergraduate medical students and GP trainees are an important group to target. Research carried out by one of the surgical attendees revealed that whilst medical students are keen to know more about melanoma, its diagnosis and treatment, there is very little taught as part of the existing undergraduate syllabus. The undergraduate medical curriculum is nationally mandated by the General Medical Council (GMC) and there is an opportunity to encourage them to broaden the skill set of future clinicians.

### **Sentinel Node Biopsy & Staging**

Sentinel Node Biopsy (SNB) is available more readily across Cancer Networks now that newer treatments are available which often require information on disease staging before initiation. It was reported by the group that approximately three quarters of Cancer Networks now offer SNBs, which was to be expected.



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### MELANOMA PATHWAY WORKING GROUP

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#### NEXT STEPS

Following on from this discussion, the group identified three core areas of clinical care that would benefit from further focused research, in order to ascertain why clinical variation exists in melanoma care. These are public awareness; the primary/secondary care interface and Specialist Skin Cancer Multidisciplinary Teams (SSMDTs). In order to investigate these broad public health, primary and secondary care elements of the melanoma pathway in more detail, it was agreed that a sub-group of the Melanoma Taskforce should be convened.

The group scoped out the three core areas for further consideration, in order to establish broad statements of quality standards in the following areas:

CORE AREA	QUALITY MEASURES FOR FURTHER CONSIDERATION	CONSTANTS
<i>Primary Care</i>	- Diagnosis - Time from presentation to excision	➤ <b>Patients</b>
<i>Dermatology</i>	- Correct excision margins	
<i>Surgery</i>	- Sentinel Node Biopsies - Time to Surgery - Complications - Readmission - Appropriate volumes	➤ <b>Cancer Specialist Nurses</b>
<i>Oncology</i>	- Access to information on clinical trials - Participation in clinical trials	
		➤ <b>Peer Review</b>

Whilst the melanoma pathway is a complex process that can vary from one clinical centre to another, one common feature must be quality. As such the objective of the working group will be to identify features of best practice melanoma care. With the NHS in a state of significant organisational flux, it is imperative that these elements of best practice are captured and shared. These findings will then inform a set of recommendations that can support commissioners to ensure that melanoma patients have access to the right quality care, at the right time, irrespective of location.

A Quality Standard for Melanoma is to be produced by NICE, but the exact timeline for this is not yet known. This sub-group of the Melanoma Taskforce is well placed to inform the development of this process



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by critically assessing the melanoma pathway and identifying the core features of optimal melanoma care in the NHS.

It was agreed that the group will be multi-disciplinary, including nurses, surgeons, GPs, dermatologists, oncologists and patient representatives so that views on all aspects of the pathway can be captured. The group is likely to operate virtually for the most part, facilitated by the Secretariat, with 1-2 face to face meetings taking place, with a view to holding the first meeting in January 2012.

At Siân James' request, Dr James Larkin, Consultant Medical Oncologist from the Royal Marsden Hospital, has agreed to chair the Taskforce sub-group. For more information on this group and to declare your interest in being a member, please contact the Taskforce Secretariat, Daniel Cambers, at [daniel@insightpa.com](mailto:daniel@insightpa.com) or 020 7824 1857.





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### APPENDIX I: SUMMARY OF PRESENTATIONS

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#### 1) MELANOMA TASKFORCE SURVEY: KEY FINDINGS

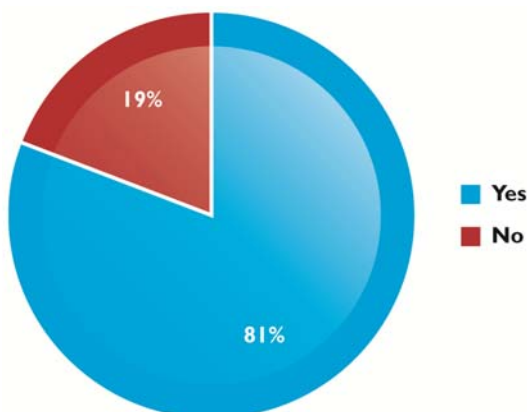
In September, the Taskforce issued a questionnaire to all Acute Hospital Trusts and Cancer Networks in England under the terms of the Freedom of Information Act 2000.

Responses were received from 72% of Acute Trusts, although several replied to say they did not hold the information requested. The information presented below is therefore drawn from the information provided by a total of 98 Trusts. Responses were received from 16 Cancer Networks, representing a 59% response rate. The figures shown in brackets below show the number of Trusts and Networks that gave answers to each question. The findings of the survey were used to inform the discussion held by the Melanoma Taskforce, as outlined above.

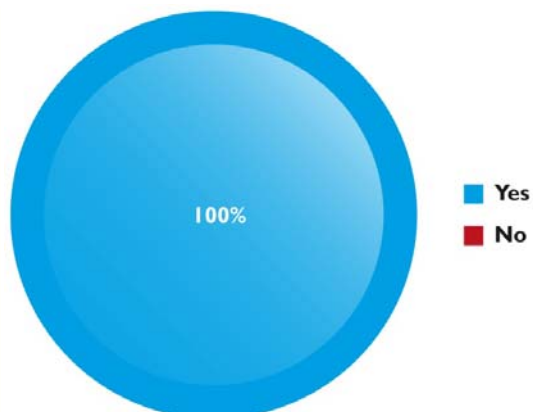
**1. Does your Trust / Network have its own standard clinical pathway for the diagnosis, management and treatment of patients with melanoma?**

<b>ACUTE TRUSTS:</b>	<b>81% (79) said 'yes'</b>	<b>19% (19) said 'no'</b>
<b>CANCER NETWORKS:</b>	<b>100% (16) said 'yes'</b>	<b>0% (0) said 'no'</b>

**ACUTE TRUSTS**



**CANCER NETWORKS**



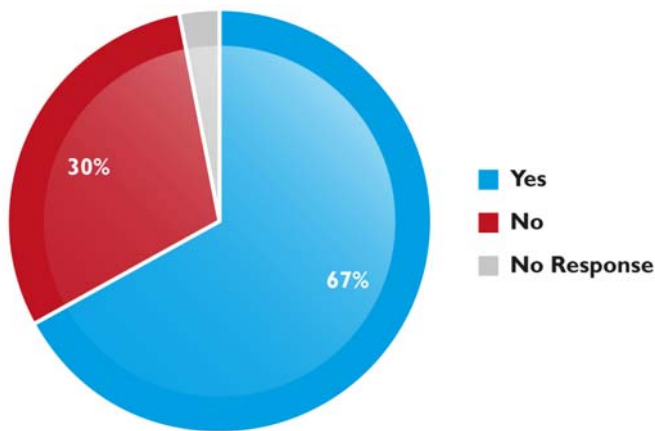


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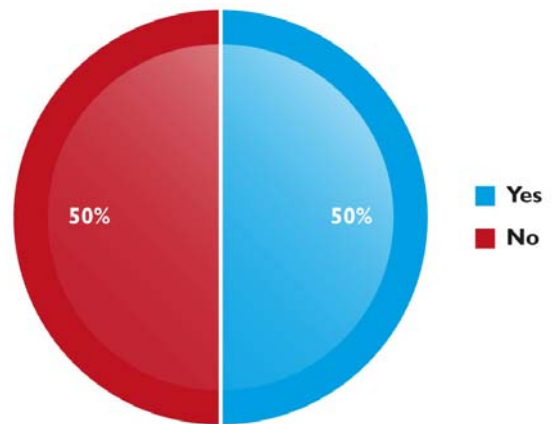
2. Do you carry out regular audits to ensure that the pathway is being followed?

ACUTE TRUSTS: 67% (66) said 'yes' 30% (29) said 'no'  
CANCER NETWORKS: 50% (8) said 'yes' 50% (8) said 'no'

ACUTE TRUSTS



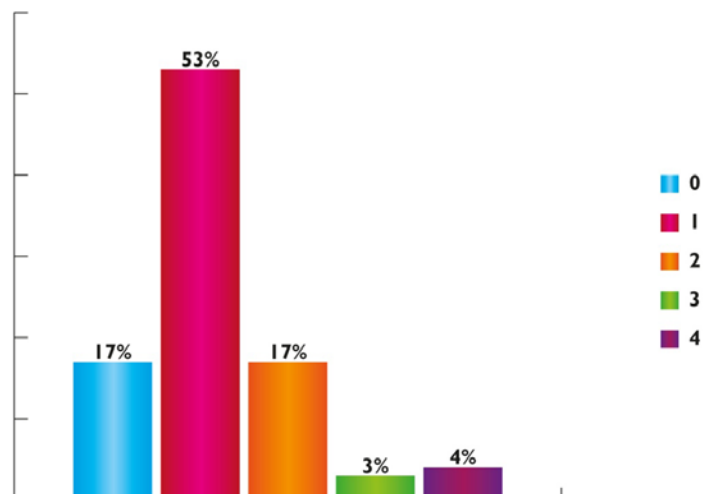
CANCER NETWORKS



3. How many melanoma nurse specialists currently practice within your Acute Trust?

0: 17% (17) 1: 53% (52) 2: 17% (17) 3: 3% (5) 4: 4% (4)

ACUTE TRUSTS





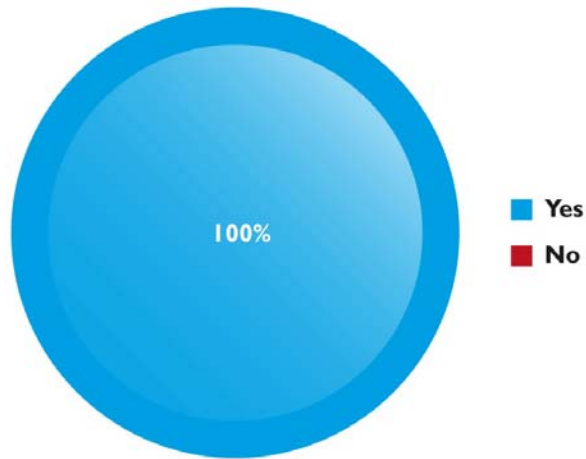
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4. Does your Cancer Network have a Specialist Skin Multidisciplinary Team (SSMDT)?

100% (16) said 'yes'

0% (0) said 'no'

### CANCER NETWORKS



5. Does your Trust / Cancer Network undertake Sentinel Node Biopsy?

ACUTE TRUSTS:

19% (19) said 'yes'

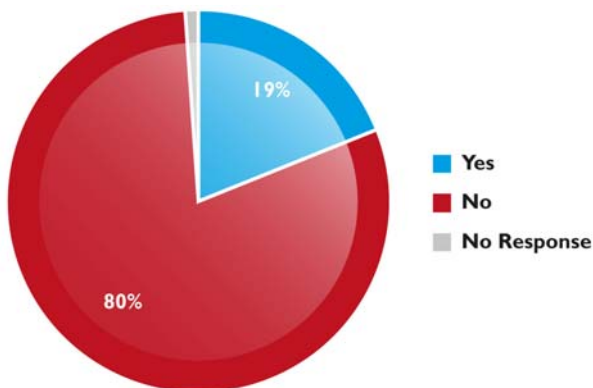
80% (78) said 'no'

CANCER NETWORKS:

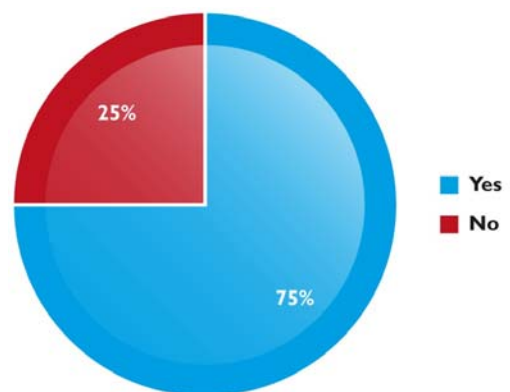
75% (12) said 'yes'

25% (4) said 'no'

### ACUTE TRUSTS



### CANCER NETWORKS



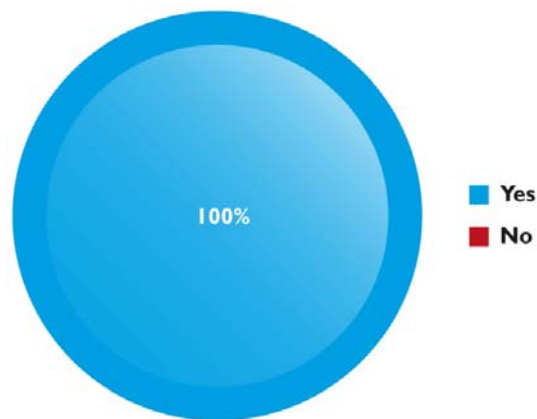


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6. Are patients routinely made aware of clinical trials taking place that may be appropriate for them?

CANCER NETWORKS: 100% (16) said 'yes' 0% (0) said 'no'

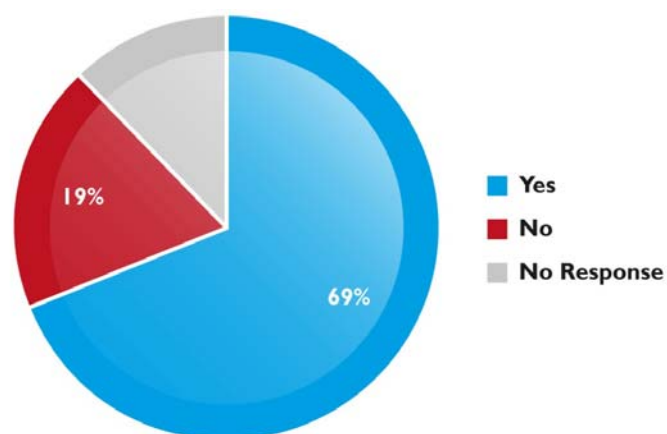
### CANCER NETWORKS



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

CANCER NETWORKS: 69% (11) said 'yes' 19% (3) said 'no'

### CANCER NETWORKS

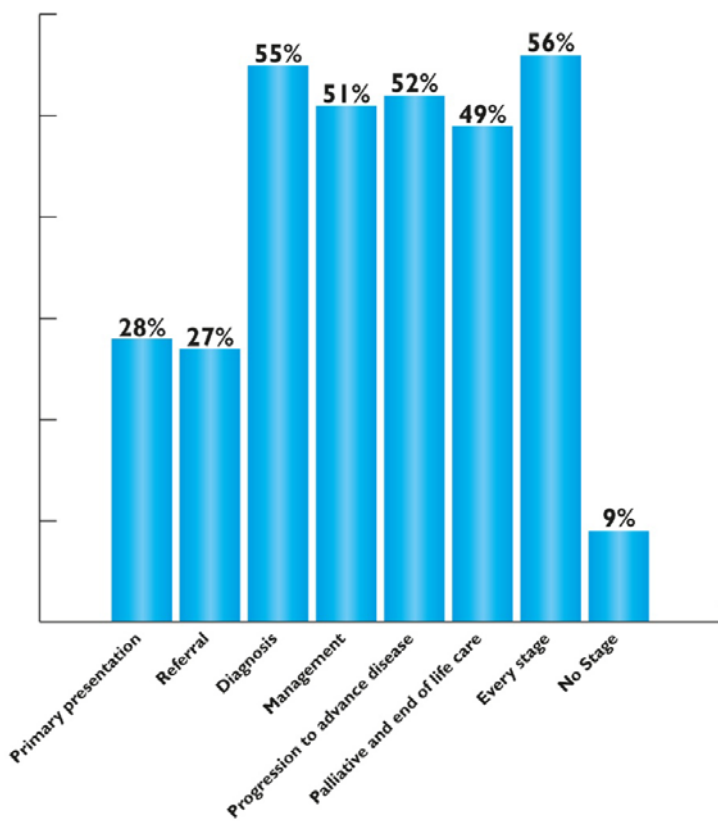




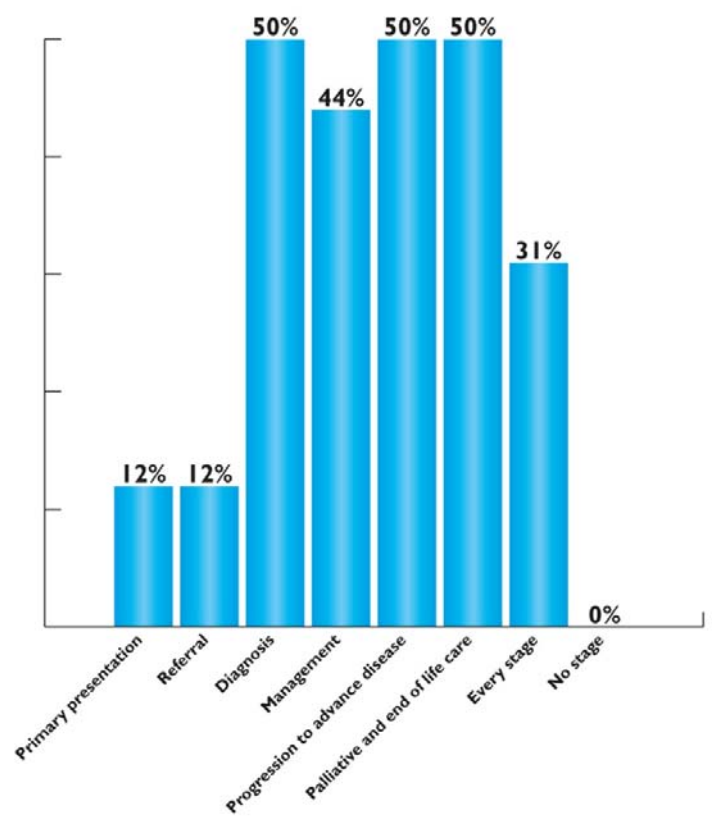
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8. At which stage does your Trust / Network provide reassurance and psychological counselling routinely for melanoma patients?

### ACUTE TRUSTS



### CANCER NETWORKS

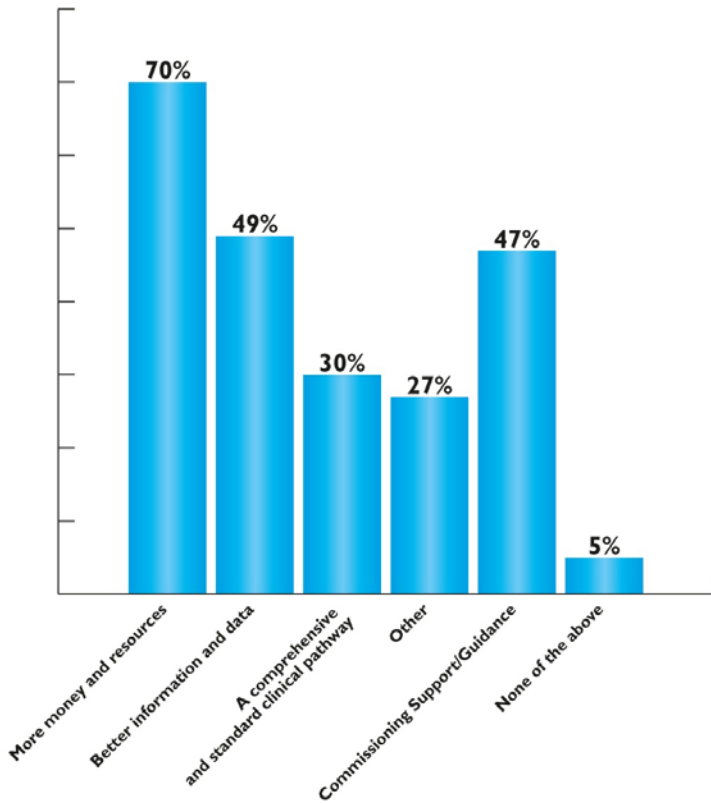




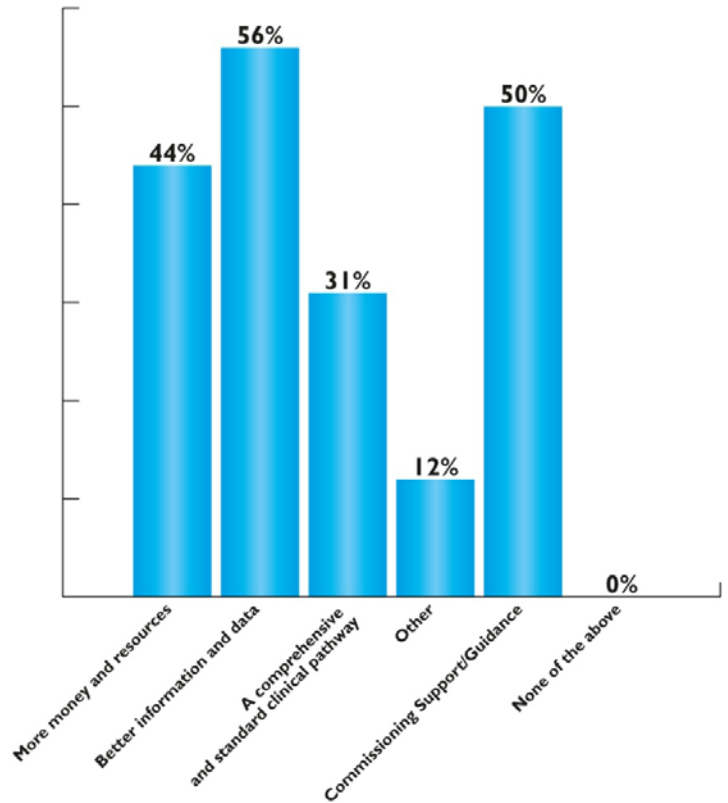
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9. Please indicate which of the following you believe would improve care for patients with melanoma.

### ACUTE TRUSTS



### CANCER NETWORKS

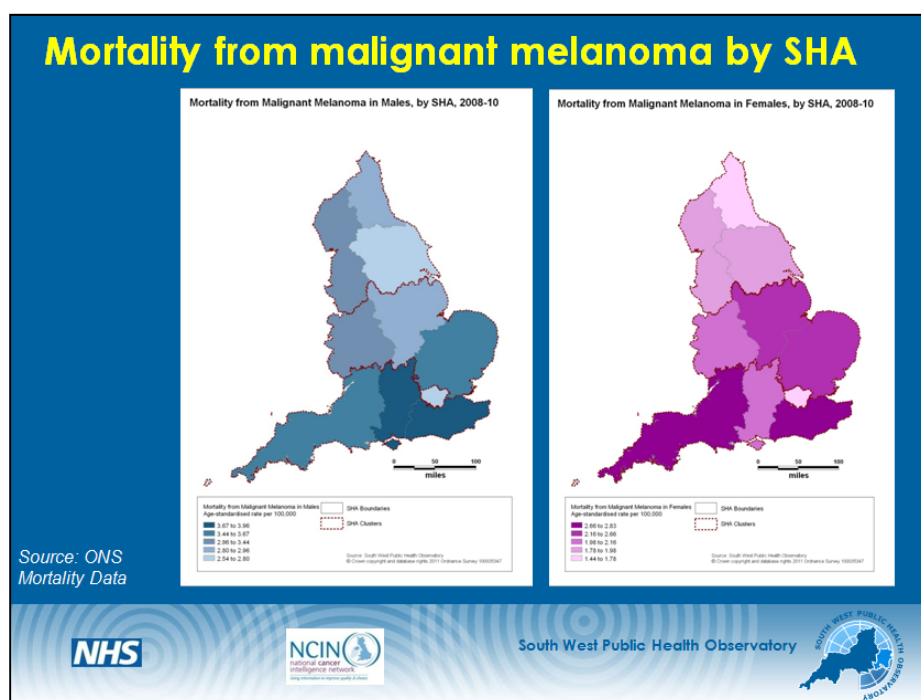
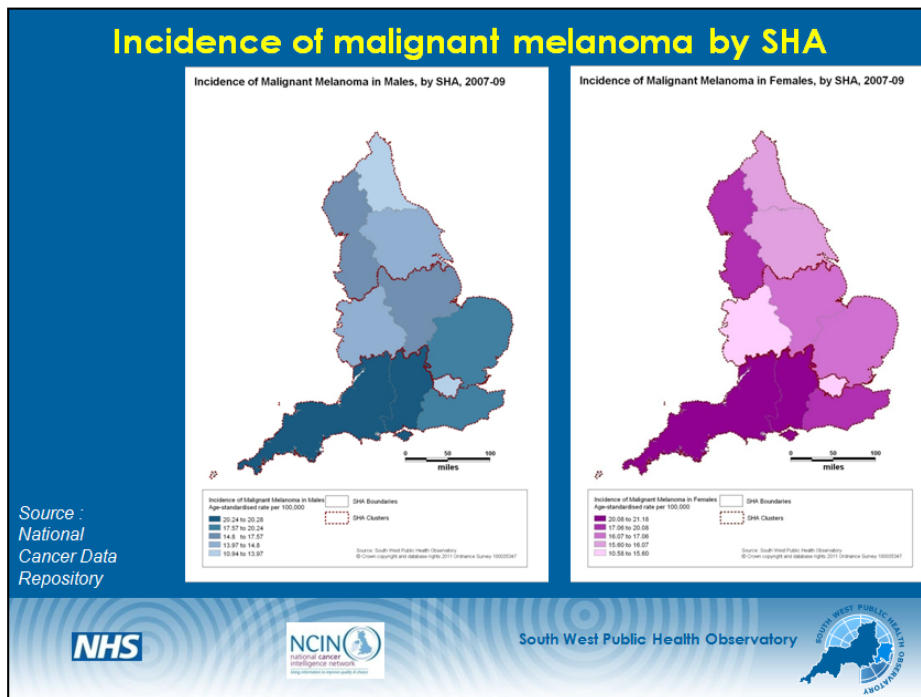




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### 2) MALIGNANT MELANOMA: INCIDENCE & MORTALITY - Veronique Poirier, South West Public Health Observatory

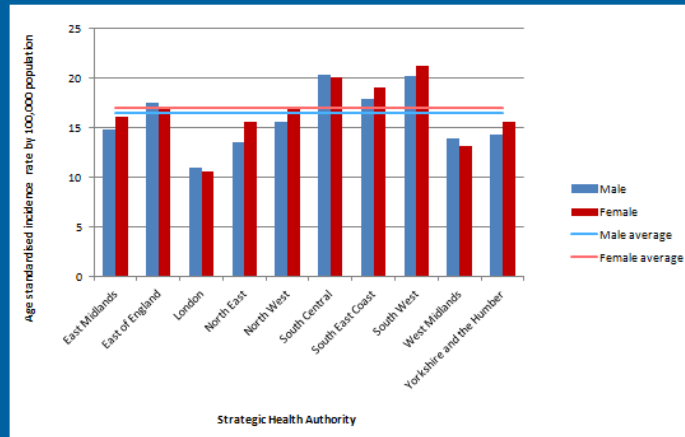
Veronique Poirier of the South West Public Health Observatory presented data on rates of incidence and mortality in malignant melanoma. The data clearly demonstrates that there is significant variation in melanoma patient outcomes across England due to, amongst other factors, variance in care provision and delivery.





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



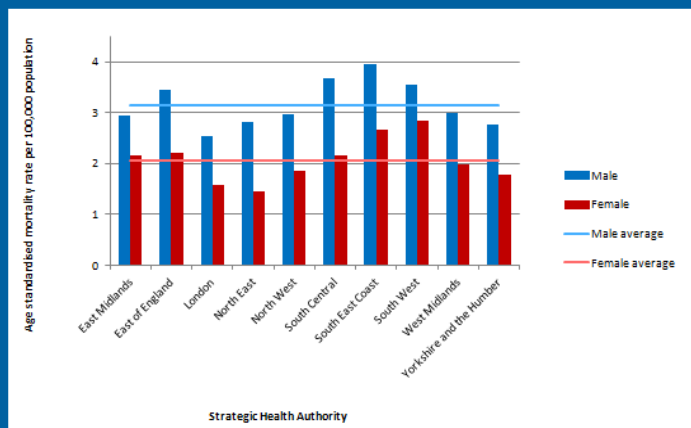
Source: National Cancer Data Repository



South West Public Health Observatory



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



Source: ONS Mortality Data



South West Public Health Observatory







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### Possible factors influencing variation across England

#### Incidence

- Composition of the population
- Socioeconomic distribution
- Sun and UV light exposure

#### Mortality

- High incidence
- Level of awareness and late presentation
- Variation of care provision and delivery



South West Public Health Observatory





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### APPENDIX II: ATTENDEES

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Kimberley Carter	-	Campaigns PR officer, British Association of Dermatologists
Sasha Daly	-	Head of Policy, Teenage Cancer Trust
Charlotte Fionda	-	Marketing Development Director, The Karen Clifford Skin Cancer Charity
Dr Jenny Geh	-	Plastic Surgeon in Skin Oncology, Guys & St Thomas' NHS Foundation Trust
Stephen Gilbert MP	-	Member of Parliament for St Austell & Newquay (Chair)
Stephen Hamilton	-	Plastic Surgeon, Royal Free Hospital, London
Denise Hancock	-	Cancer Nurse Specialist Skin Cancer and Melanoma, University Hospital Southampton NHS Foundation Trust
Sarah Henderson	-	Media Relations Manager, Teenage Cancer Trust
Anthony Hubbard	-	Technical Director, Skcin, The Karen Clifford Skin Cancer Charity
Dr James Larkin	-	Consultant Medical Oncologist, Royal Marsden NHS Foundation Trust
Chris Lunn	-	Health Campaign Manager, Cancer Research UK
Deborah Mason	-	Communications Manager, British Association of Dermatologists
Victoria McMorran	-	Macmillan Skin Cancer Nurse Specialist, Addenbrookes Hospital
Veronique Poirier	-	Senior Cancer & Public Health Information Analyst, South West Public Health Observatory
Barry Powell	-	National Clinical Lead for Skin Cancer
Dr Dafydd Roberts	-	Consultant Dermatologist, ABM University Hospital Trust
Dr Neil Shroff	-	Accredited GPwSI Skin Cancer; Committee Member, Primary Care Dermatology Society
Martin Whitehead	-	Bristol Myers Squibb
Daniel Cambers	-	Melanoma Taskforce Secretariat
James Tyrrell	-	Melanoma Taskforce Secretariat

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