



## Malignant melanoma in Northern Ireland

### Introduction

Skin cancer is the most common cancer in Northern Ireland<sup>1</sup>. There are two main types of the disease: non-melanoma skin cancer and malignant melanoma. Non-melanoma skin cancer is more common with over 3,000 cases diagnosed in 2010<sup>2</sup>. Malignant melanoma is relatively rare by comparison, with around 270 people diagnosed every year<sup>3</sup>. However, it is more serious, with 66 deaths from malignant melanoma in 2010<sup>4</sup>.

In recent years, there has been increasing awareness and understanding among the public of the causes, signs and symptoms of skin cancer. This has been helped by the effective work of many campaigners and policy-makers in Northern Ireland. For example, the first skin cancer prevention strategy in the UK was published in 1997 in Northern Ireland, by the Department of Health, Social Services and Public Safety (DHSSPS).

This focus on improving awareness and early detection of skin cancers has continued in Northern Ireland with the publication in 2011 of the *Skin Cancer Prevention Strategy and Action Plan 2011-2021*<sup>5</sup>. This is a positive step forward in helping to increase understanding of the risks associated with exposure to UV light which should drive changes in behaviour that, over time, reduce the growing rate of skin cancer incidence. However, despite this progress, the numbers of people in Northern Ireland being diagnosed with malignant melanoma are increasing<sup>6</sup>. Significant challenges still need to be overcome and more work is needed to improve the quality of care available to patients and to increase survival rates.

This briefing provides an overview of some of the key statistics for malignant melanoma in Northern Ireland and identifies areas where improvements to services could be made.

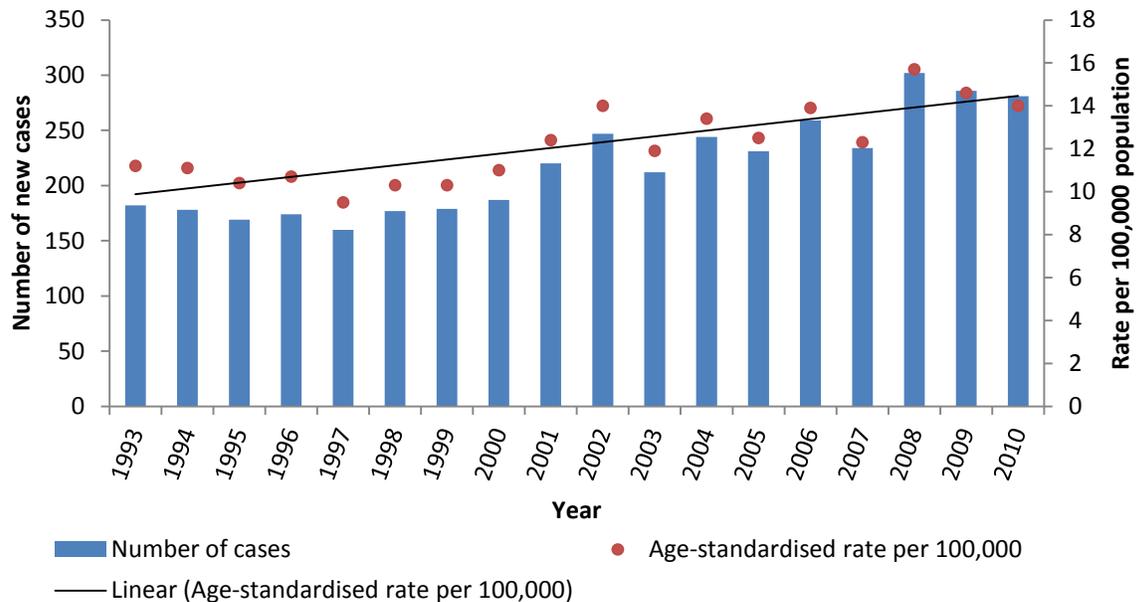
### Burden of malignant melanoma in Northern Ireland

#### Incidence of malignant melanoma

In 2010, a total of 11,269 new cases of cancer were diagnosed in Northern Ireland<sup>7</sup>, of which 281 were for malignant melanoma<sup>8</sup>, making it the sixth most common form of cancer. This represents 3.4% of all cases of cancer and equates to an incidence rate of 14 per 100,000 population<sup>9</sup>.

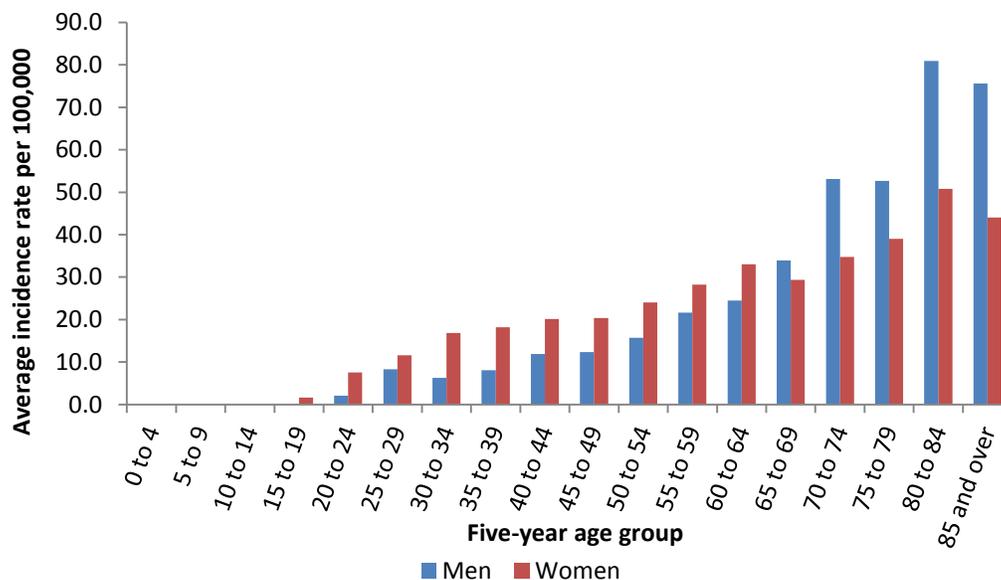
Incidence rates for malignant melanoma have increased consistently over the last two decades with the number of cases diagnosed increasing from 182 in 1993, to 281 in 2010.

**Figure 1 - Number of new cancers and age-standardised incidence rate for malignant melanoma (1993-2010)<sup>10</sup>**



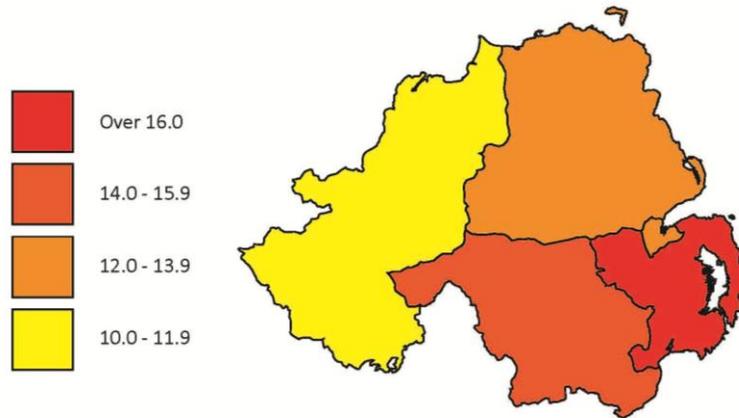
Melanoma is more common in women than in men; 165 cases were diagnosed in women in 2010, and 116 cases were diagnosed in men<sup>11</sup>. In addition, although the risk of malignant melanoma increases with age, it is one of the most common cancers among those in the 15-34 age group. Figure 2 illustrates the age profile of people diagnosed with malignant melanoma in Northern Ireland<sup>12</sup>.

**Figure 2 - Average melanoma incidence rate per 100,000 by age and by sex in Northern Ireland (2006-2010)<sup>13</sup>**



There are differences in the incidence rates of malignant melanoma in different parts of Northern Ireland. Figure 3 shows the regional patterns in incidence in Northern Ireland. Over the period 2006-2010, malignant melanoma incidence rates were lowest in the Western Health and Social Care Trust (11 cases per 100,000) with the South Eastern Health and Social Care Trust (16 cases per 100,000) and the Northern HSC Trust (13 cases per 100,000) having the highest levels<sup>14</sup>.

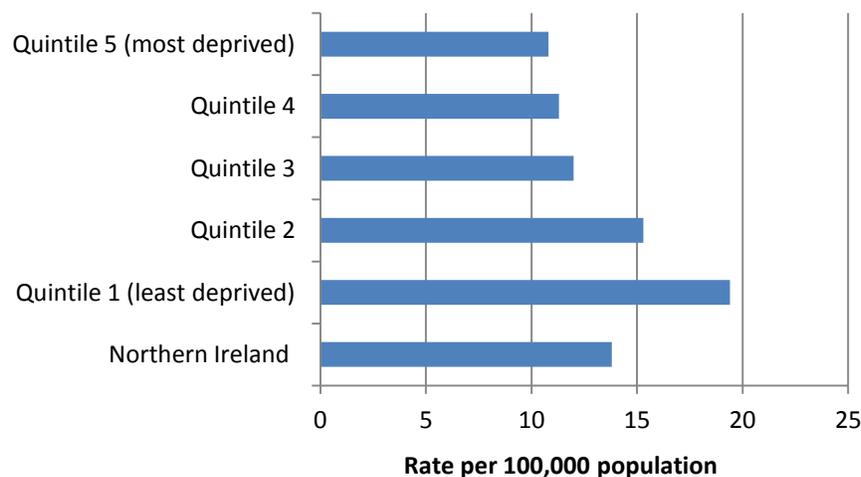
**Figure 3 – Average malignant melanoma incidence rates by health and social care trust (2006-2010)<sup>15</sup>**



### Deprivation and malignant melanoma

Most cancers are linked with deprivation, with higher rates of cancers and lower survival rates in people from the most deprived areas. However, rates of melanoma are associated with affluence. Average incidence rates for malignant melanoma were highest in the least deprived area, by contrast, rates were lowest amongst the most deprived areas<sup>16</sup>.

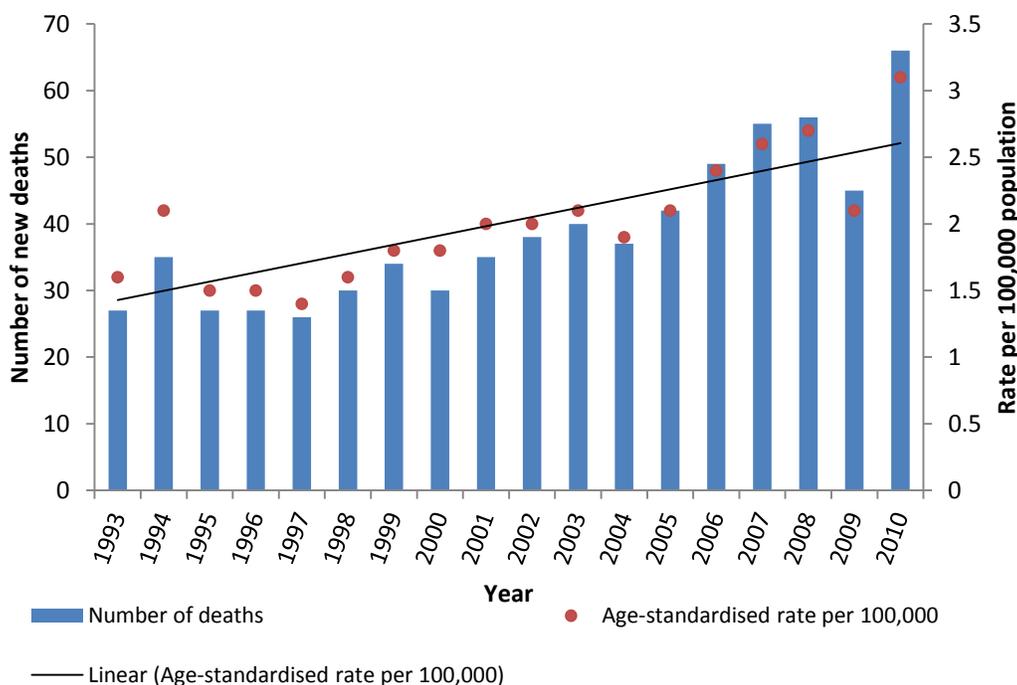
**Figure 4 - Age-standardised incidence rate for malignant melanoma by deprivation (2006-2010)<sup>17</sup>**



## Mortality and survival rates

There were 66 deaths from melanoma in Northern Ireland in 2010. As Figure 5 shows, mortality rates have risen steadily since 1993. This increase has been most pronounced amongst men, with a four-fold increase from 1 to 4 deaths per 100,000 across this period<sup>18</sup>. Mortality rates rise with age, with over half of all deaths from melanoma in 2010 occurring in people over 70, reflecting the age profile of incidence<sup>19</sup>. As with incidence rates, average mortality rates for melanoma were also highest in the least deprived area and lowest in the most deprived<sup>20</sup>.

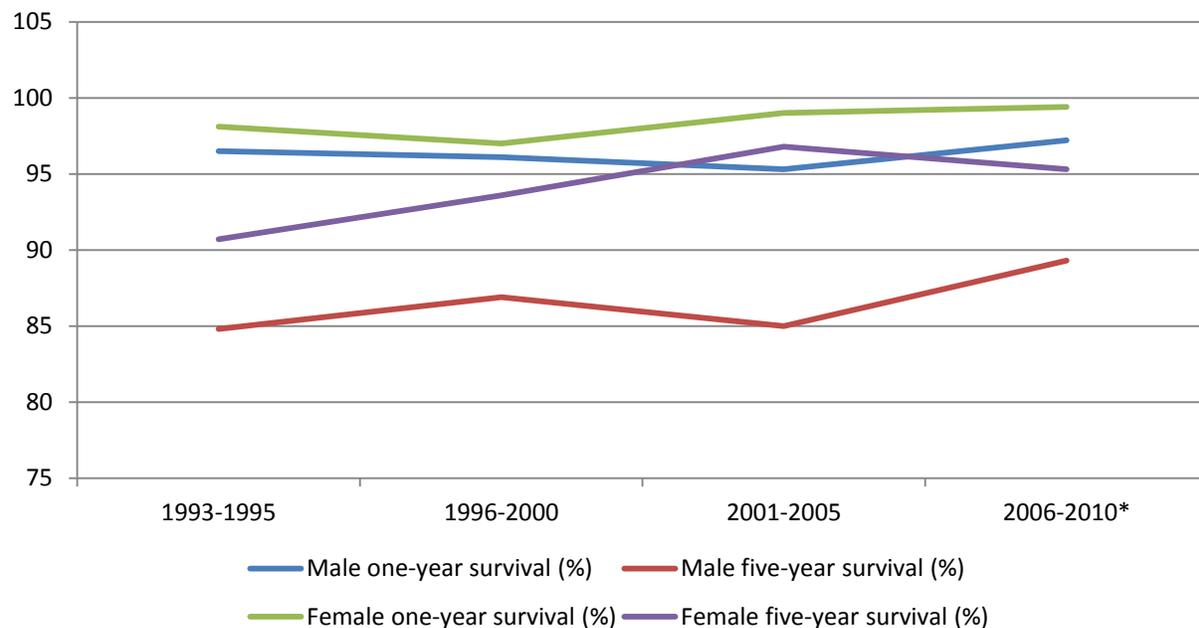
**Figure 5 – Number of new cancers and age-standardised mortality rate for malignant melanoma (1993-2010)<sup>21</sup>**



Over the last 20 years, survival rates for malignant melanoma have been high and fluctuated only marginally, with one- and five-year survival rates for women consistently higher than for men. Figure 6 below sets out the age-standardised rates of relative survival for men and women.

One possible explanation for the differences in survival rates between men and women could be that malignant melanomas in men are more often found on less visible parts of the body. This can lead to a delay in patients spotting the signs and symptoms and therefore the tumour being more advanced by the time of the diagnosis. Across the UK, 41% of melanomas in men are found on the trunk, particularly the back, whereas for women 40% of melanomas are found on the leg<sup>22</sup>. However, there are likely to be a range of complex factors that play a part in the differences between survival rates, such as the propensity to seek early medical advice<sup>23</sup>.

**Figure 6 – Age-standardised malignant melanoma cancer relative survival rates, 1993-2010<sup>24</sup>**



### Assessing the quality of care and treatment

Statistics on the incidence of malignant melanoma and mortality and survival rates are helpful in providing an insight into where the burden of melanoma falls in different parts of the country. However, it is not possible to draw conclusions from these data about the quality of care and treatment.

### Quality standards

It is welcome that the DHSSPS has introduced a *Service Framework for Cancer Prevention, Treatment and Care*<sup>25</sup> and we support the principles of prevention, early detection and effective treatment and care of cancers. However, it is of significant concern that the standards that specifically relate to skin cancer only mention basal cell carcinoma and do not include standards for the treatment or care of people with malignant melanoma. As has been set out above, the survival rates for people with malignant melanoma are relatively high but this does not mean that the NHS can be complacent about this cancer. There were still 66 deaths from malignant melanoma in Northern Ireland in 2010<sup>26</sup> and improvements must be made to services to reduce this number in future. This will include ensuring:

- People are aware of the signs and symptoms of skin cancer and when to seek professional advice
- Professionals understand the signs of skin cancer and how to refer people swiftly for specialist treatment
- Pathways are in place to secure swift treatment for people with malignant melanoma
- Securing funding for new treatments, including diagnostic testing so that people can benefit from the development of targeted medicines



We urge the DHSSPS to review and update the standards on skin cancer to include standards on the treatment of people with malignant melanoma.

In addition, although the Service Framework is in place and is intended to improve service provision in Northern Ireland, there is not currently a systematic way to collect data to assess progress. It is important as the Framework is implemented that the DHSSPS monitors the progress by Health and Social Care trusts and encourages progress across the country. This will help individual trusts to ensure that their services are delivering improved outcomes for patients and enable the Health and Social Care Board to identify areas where additional support is required.

### **Patient experience**

The Patient and Client Council is the body responsible for ensuring that the voice of patients and carers is heard and acted on within the NHS. In response to a consultation from the Council, people in Northern Ireland have already identified cancer services as one of their key priorities for the health service<sup>27</sup>. It would be helpful for the Council to give voice to patients with cancer. We recommend that the Council introduces a patient experience survey for people with cancer in Northern Ireland, similar to that run in England<sup>28</sup>. This would provide Health and Social Care trusts with reliable data and insights into various aspects on patients' experiences including:

- Waiting times for appointments and whether patients have to make multiple visits to get a diagnosis
- The information provided to patients on their cancer
- Whether patients were offered a choice of treatment and support to manage side-effects
- Access to a clinical nurse specialist

Such a survey would allow the health service to measure progress in delivering high quality care to patients, including again the Service Framework for Cancer. It could also be used to:

- Support patients to make informed choices about their care
- Provide information to allow the Health and Social Care Board to secure improvements in care through strong contract management
- Enable local service providers to identify where improvements are most needed
- Allow local services to compare their performance with other services

### **Access to treatments in Northern Ireland**

Treatment options for patients with advanced or metastatic malignant melanoma have historically been limited. However, in the last year there have been major breakthroughs in treatments, with the introduction of two new medicines<sup>29, 30</sup>. Despite these developments, there is a risk that patients in Northern Ireland will be unable to benefit from these life-extending treatments.



Cancer patients in Northern Ireland have long been at a particular disadvantage, compared with the rest of the United Kingdom, in securing access to drugs approved by the National Institute for Clinical Excellence (NICE). In recognition of this, in September 2011 the DHSSPS announced the introduction of new arrangements for reviewing and endorsing NICE guidelines in Northern Ireland aimed at streamlining and expediting the process<sup>31</sup>.

The new guidance stipulates that the review process should be concluded within four weeks of the final publication of guidance by NICE. Trusts are also expected to confirm after three months that targeted dissemination took place and that an implementation plan is in place<sup>32</sup>.

Given the lack of alternative treatment options for people with malignant melanoma, we believe that it would be appropriate for these guidances reviews to be included in the audit conducted by the Guidelines and Audit Implementation Network<sup>33</sup> to ensure that there is consistent access to these medicines across the country.

## Conclusion

Despite the existence of the *Skin Cancer Prevention Strategy and Action Plan 2011-2021*, the incidence of malignant melanoma in Northern Ireland is increasing. Alongside important prevention efforts, there needs to be a focus on improving the quality of services for people with malignant melanoma to help improve patients' outcomes. There are several steps that can be taken to achieve this:

- The Department for Health, Social Services and Public Safety should collect and publish data on progress with the implementation of the *Service Framework for Cancer Prevention, Treatment and Care*
- The Patient and Client Council should conduct a survey of cancer patients' experiences, similar to that conducted in England, to highlight areas where progress is required
- The NICE technology appraisals on the new treatment options for patients with malignant melanoma should be reviewed and endorsed as swiftly as possible to ensure patients in Northern Ireland have consistent access to these new medicines

## Contact details

Skin Cancer UK is a coalition of professional groups and charities administered by Skcin (The Karen Clifford Skin Cancer Charity), committed to tackling this preventable cancer.

If you would like to find out more information about how you can support the charity, please contact Charlotte Fionda on [charlotte.fionda@skcin.org](mailto:charlotte.fionda@skcin.org), or 07834 450671.

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