Variability of skin cancer registration practice in the United Kingdom

G Maudsley, E M I Williams

Merseyside and Cheshire Cancer Registry produced a skin cancer bulletin to raise awareness as part of the Health of the Nation activity. The media focused on the reported local excess of 17% (standardised registration ratio = 117 for 1987–91 compared with England and Wales; 95% confidence interval, 114, 119),1 and an increasing age standardised incidence rate for skin cancer over the 1970s and 1980s. The excess was difficult to interpret, partly because the national reference is influenced by anecdotal known variations in registration practice—ie those lesions that registries intend to register. The English skin cancer target—"to halt the year-on-year increase in the incidence of skin cancer by 2005"—relies on cancer registration data. Even before considering case ascertainment and accuracy, measuring progress is difficult because:

- Registration practice is variable and undocumented;2
- The target is unquantified and ambiguous. For example, does it mean that the incidence should plateau by 2005, or does subsequent mention of a 1986 “baseline" mean that incidence should return to this by 2005?

This study aimed systematically to document major inter-registry variations in skin cancer registration practice, firstly, with reference to Health of the Nation monitoring in England, and, secondly, geographic comparisons within the United Kingdom (UK).

Methods

A brief questionnaire investigated whether all lesions in four main subgroups of skin cancer (basal cell carcinoma, squamous cell carcinoma, cutaneous malignant melanoma, and “other skin cancers”) were registered separately and fully. The questionnaire was distributed with reply paid envelopes to the directors of all 18 UK cancer registries in June 1994, followed by repeat questionnaires to non-responders two months later. Each registry checked its entry in table 1, in January 1996.

Results

All registries responded (table 1). Only 3/11 English and 2/7 other UK registries registered every lesion (ie including “multiples”) from the four categories, and there was considerable inter-registry and inter-category variation. The commonest practice for basal cell carcinoma (11/18) was effectively to register the “first only” in any individual. Registration practice elsewhere in the UK was slightly more uniform for the other three cancer categories than in England.

Only 7/11 English and 1/7 other registries recorded Breslow thickness and Clark’s level to stage cutaneous malignant melanoma—the rest recorded neither.

Discussion

This study was time consuming but showed substantial nationwide variations in registration practice. Such variations were unhelpful in interpreting the Merseyside and Cheshire excess of skin cancer to local media, although the excess mortality for males with non-melanoma skin cancer implied a real increase in incidence. Despite being important indicators of quality assurance in skin cancer registration, case ascertainment, timeliness, record completeness, and the validity of “registrations” are irrelevant for cancers that registries do not attempt to record.

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**Table 1** Registration practice in United Kingdom (UK) cancer registries for cancer and in situ carcinoma of skin (registrations in mid-1994*)

<table>
<thead>
<tr>
<th>Registry</th>
<th>Skin lesions registered†:</th>
<th>Cancer</th>
<th>Non-melanoma skin cancer</th>
<th>Malignant melanoma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In situ carcinoma</td>
<td>Basal cell carcinoma</td>
<td>Squamous cell carcinoma</td>
<td>Other skin cancer</td>
</tr>
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<td>England:</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>1 Merseyside &amp; Cheshire</td>
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<td>2</td>
<td>+</td>
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<td>+</td>
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<td>Elsewhere in UK:</td>
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<td>15‡</td>
<td>+</td>
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</tr>
</tbody>
</table>

* Year of diagnosis varies.
† Registered—accessible on the computerised registry database. Guidelines exist about when second or subsequent lesions of the same type should be registered as true "multiples" (synchronous or metachronous).
‡ At these registries, the total number of lesions (including those of skin) registered per patient = 5 irrespective of site and type.

Key:
+ all
- none
* only first
+ only first, but affected by the limit on total number of registrations per patient
† only first of each morphology (eg a nodular and a superficial spreading malignant melanoma counts as two registrations)
‡ not all, because affected by the limit on total number of registrations per patient
§ for staging of cutaneous malignant melanoma: n = node, b = Breslow thickness, c = Clark’s level, o = other; and b/c means that b recorded in preference to c if both present, and c recorded if b absent

NB There were no major changes in registration practice by January 1996.

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(†) Epidemiol Commun Health 1997;31:337–338)
Basal cell carcinoma is often multiple,\(^3\) providing an extreme example of the problems with registering all “multiple” neoplasms. Basal cell carcinoma is also the commonest skin cancer (eg locally, “first” basal cell carcinomas account for approximately three quarters of skin cancer\(^5\)). As expected, perhaps, but previously undocumented systematically, basal cell carcinoma registration is sufficiently variable to distort target setting and monitoring. Although the Scottish, Welsh, and Northern Irish health strategies do not contain an English-style skin cancer target,\(^3\) variable registration practices complicate comparisons with England.

Cynically, an impressive reduction in skin cancer incidence could follow if all English registries copied the minority—not registering basal cell carcinoma at all! Arguably, the workload is unwarranted for the favourable prognosis and likely data quality problems involved. Consensus about, for example, whether someone with three basal cell carcinomas is counted once (“person based”) or thrice (“tumour episode based”) would reduce the variable regional input into the national dataset thereby improving incidence accuracy and target setting. Person based and episode based data have their merits. These are informing prevention and measuring service use respectively. Furthermore, a standard approach to skin cancer registration would allow best use of scarce registration resources. Concern about worldwide variation in non-melanoma skin cancer registration practice has led to “total cancer incidence” being published including and excluding such cases, illustrating that this problem extends beyond the UK.\(^3\)

The model core contract for cancer registries could have clarified this registration problem, but apparently excludes non-melanoma skin cancer from the required dataset.\(^6\) For cutaneous malignant melanoma, recording stage has yet to become universal.

Appropriately, much effort is directed at skin cancer prevention. The problems lie in target setting and monitoring. A person based skin cancer target, or one excluding non-melanoma skin cancer, could rationalise monitoring, but would ignore the personal and health care consequences for affected people. An option appraisal, of the costs and consequences of skin cancer registration, is therefore recommended to ensure that decisions about practice become evidence based.

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