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CANCER OUTCOMES MONITORING

REGISTRATION OF SKIN CANCER IN YORKSHIRE

A Study into the Completeness & Validity of Cancer Registry Data

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Registration of Skin Cancer in Yorkshire

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Report Produced by

NY CRIS *Northern & Yorkshire* **Cancer Registry & Information Service**

The Leeds Teaching Hospitals NHS Trust

in collaboration with the

Research School of Medicine

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2.1. ACKNOWLEDGEMENTS

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3 EXECUTIVE SUMMARY

1. The primary objectives of this study were: an assessment of the completeness of skin cancer registration in the former Yorkshire NHS Region in the year 1994; an estimation of the number of additional skin cancer cases that were not captured by the registration process in 1994 and a consideration of methods for the future improvement of registration completeness.
2. New diagnoses of skin cancer for 1994 were ascertained from four separate information sources within the Region: pathology laboratories, inpatient databases available on hospital patient administration systems (PAS), outpatient clinic listings and general practices. The PAS included information about patients undergoing removal of skin lesions in plastic and general surgical outpatient clinics but not procedures carried out in dermatological outpatient clinics.
3. Information was returned from 14 of the 16 pathology laboratories, 16 of the 17 hospital patient administration systems and 123 of the 661 general practices within the former Yorkshire Region. A survey of patient diagnoses within relevant outpatient clinics was carried out covering a one-month period in each of seven hospitals.
4. Information was obtained concerning 3853 patients with new diagnoses of skin cancer (255 with malignant melanoma) from pathology laboratories, 2999 (311 melanoma) patients from hospital PAS inpatient returns, 192 (16 melanoma) patients from the outpatient note review and 565 (61 melanoma) patients from the general practitioner responses. A proportion of these notifications duplicated each other and after excluding these, information was available on 6120 (502 melanoma) patients.
5. Of the 6120 identified patients, 5113 (84%) had a matching cancer registry record. There were 439 matches (87%) for patients with malignant melanoma and 4558 (83%) matches for patients with non-melanoma skin cancer (either squamous cell or basal cell skin cancer).
6. The information provided in paragraph 5 relates to skin cancer patients identified from all data sources and is not specific for patients diagnosed in 1994. Of the identified skin cancer patients who had a matching cancer registry record, approximately 40% were matched with a record for a registration year other than 1994. This arises mainly because some patients with a second (or later) basal cell carcinoma in 1994 would be matched with a registration from an earlier year, the diagnosis not being registered more than once.
7. For the information received from pathology laboratories, hospital PAS inpatient returns and the outpatient note review, the proportions of patients with a matched cancer registry record were similar: 85%, 89% and 88% respectively, 90%, 92% and 81% (the latter based on only 13/16 matched cases) for malignant melanoma and 85%, 89% and 89% for non-melanoma skin cancer. The matched proportions for the patients identified by general practitioners were lower than this, 71% for both malignant melanoma and non-melanoma skin cancer.
8. Patients identified by two or more sources were more likely to have a matched registry record than those identified by a single source. Thus 95% of all patients identified from pathology laboratories and hospital PAS returns had a matched record compared with 80% and 85% if identified by either source alone.

9. There was considerable variation in the likelihood of identified patients being matched with a registry record according to the hospital Trust and the area of residence of the patient. For example, the proportion of matched records from pathology laboratories varied from 32% (Pontefract) to 98% (Dewsbury).

10. Of the 5113 identified cases with a matched cancer registry record, 283 (5.5%) had a different histological diagnosis from that in the original source data. Of the 439 matched patients with malignant melanoma, 397 had a registry diagnosis of malignant melanoma. Of the 4558 matched patients with non-melanoma skin cancer, 4345 patients (95%) had a non-melanoma skin cancer diagnosis on the cancer registry database.

11. It was estimated that 283 (93%) malignant melanoma and 2250 (89%) patients identified from hospital PAS returns had pathological confirmation of the skin cancer. For patients identified from the outpatient clinic survey, these figures were 12 (80%) and 127 (90%) respectively while from those identified in general practice, they were 41 (72%) and 347 (72%). Those cases without evidence of confirmation either never had samples sent to pathology or these patients never had skin cancer.

12. Hospital PAS information varied considerably in its level of completeness. For example, five hospitals had less than 10 patients recorded on their PAS systems with a diagnosis of skin malignancy in the whole of 1994. Also it was impossible to distinguish between squamous cell cancer of the skin and basal cell carcinoma using PAS information.

13. In 1994 an estimated 72 additional malignant melanoma and 861 non-melanoma skin cancer cases could have been expected to have been registered in Yorkshire if all information sources had provided all their cases. This represents an increase of 23% in malignant melanoma (on the recorded figure of 309 patients) and 27% in non-melanoma skin cancer (on the recorded figure of 3166 patients). The major component to these increases is information obtained from pathology laboratories representing 40% of the additional malignant melanoma and 59% of the additional non-melanoma skin cancer.

14. In terms of overall cost-effectiveness, ensuring the complete capture of pathology information would result in the biggest impact on registration ascertainment and 90% of all skin cancers would be registered. Each of the other sources of information (hospital PAS, outpatient clinic surveys, and general practice), if complete, would each improve the registration rate by a few percentage points.

15. Approximately 10% of malignant melanoma and 16% of non-melanoma skin cancer cases, that had been histologically confirmed, were not registered. This most likely represents a failure to report information to the Registry. There was considerable variation between hospitals in the level of successful reporting.

16. There was significant variation between hospitals in the completeness of PAS information such that, by itself, it would be impossible to use for routine notification. If obtained by registries periodically, it would represent a readily available source of confirmatory information.

17. Currently no mechanisms are in place for the routine capture of information from outpatient clinics or general practice. Until such systems exist, the best mechanism for capturing skin cancer diagnoses made in these locations would be through the pathology laboratories. It is, therefore, essential to obtain histological verification of all such cancers.

18. Recommendations:

- Cancer registries should have systems in place to ensure complete ascertainment of all skin cancer diagnoses made in pathology laboratories.
- All skin cancer patients should have histological confirmation of their cancer, especially those diagnosed in outpatient clinics or in general practice.
- Periodic quality control checks are required to ensure reliability and completeness of data transfer from pathology laboratories to cancer registries.
- Hospital PAS information can be used as an independent, routinely available data source to cross check and aid in the quality control of information from pathology laboratories. By itself, PAS information is neither sufficiently complete nor reliable to act as a primary source of cases.
- Information from outpatient clinics and general practice cannot be routinely used as a primary notification source about skin cancer using current systems.

4 INTRODUCTION & BACKGROUND

Skin is the most common site of malignancy in much of the developed world. In the UK, registration rates for new skin cancer cases have increased steadily over recent decades. In England and Wales alone, more than 39,000 skin cancer cases are registered annually (ONS, 1999). The next two most common cancer sites are lung and breast, both with approximately 33,000 new cases annually (ONS, 1999).

The three main histological types of skin cancer are basal cell carcinoma (BCC), squamous cell carcinoma (SCC) and malignant melanoma (MM). The majority of skin cancers are attributed to BCC (72%), which is commonly grouped with SCC into a group of non-melanoma skin cancer (NMSC). The incidence of NMSC has doubled since the late 1970s (Yorkshire Cancer Organisation, 1996). NMSC has an excellent record of successful treatment and the prognosis for patients with these cancers is very good with five year survival rates approaching 100% (YCO, 1996). Although NMSC is associated with low mortality, it does cause considerable morbidity and, as the incidence of NMSC increases with age, the cost of treatment forms an increasing burden to health care services in an ageing population (Lucke *et al*, 1997).

In many European countries MM is the cancer showing the most rapid increase in incidence. Incidence and mortality of MM have increased by a rate of between 3 and 7% per year in several European countries (Osterlind, 1992). It is, however, much less prevalent than NMSC and in Yorkshire accounts for 9% of all skin cancers and 1.5% of all malignancies (YCO, 1996). MM is associated with considerably more serious and fatal consequences than NMSC. Generally, around 78% of cases are alive five years from diagnosis (YCO, 1996). Unlike many other cancers, a proportionally large number of cases are diagnosed in young and middle age people.

A continuous and on-going increase in the number of registered skin cancers throughout England and Wales prompted a 1992 Health of the Nation objective of halting the year on year increase in incident cases by 2005 (Department of Health, 1992). Health promotion campaigns, with the aim of promoting greater caution with respect to sun exposure, have been initiated in the UK (Sabri *et al*, 1996) with encouragement towards increased use of sunscreen, protective clothing and avoidance of exposure to high-ultra violet intensity sunlight. Health education programmes have also been directed towards informing and educating the public about how vital it is to recognise early signs of skin cancer and seek medical attention.

The only routine means available to monitor trends in skin cancer incidence is by using information obtained from population-based cancer registries. Any significant lack of completeness in the registration of skin cancer will, however, affect the validity of such information and present a significant problem in demonstrating whether the Health of the Nation objective has been met or whether health promotion activities have been successful. Incomplete registration may also detrimentally affect the planning and evaluation of local skin cancer services as well as any clinical and epidemiological studies that are dependent upon population-based cancer registry data.

Pathology reports are usually the single most important source of information used by registries to record incident cases for all forms of cancer. However, unlike most other cancers, skin cancer patients are frequently treated entirely within general practice or hospital outpatient clinics. Histological confirmation may often not be sought for these malignancies and such patients have, therefore, a high likelihood of not being registered. In addition some skin cancer patients are treated with procedures (e.g.

cryotherapy and curettage) that do not produce samples which can be histologically examined and these patients may also miss registration.

Because MM has a more serious and fatal nature than NMSC, histological confirmation is usually obtained by those responsible for management of the disease. This process is thought to result in higher case ascertainment levels throughout the country for MM than for NMSC. Recent studies indicate, however, that there is also considerable under-registration of MM (Melia *et al*, 1995; Richards *et al*, 1995).

4.1.1. Skin Cancer in Yorkshire (1991-1996)

▼ **Skin Cancer in Yorkshire – Summary Statistics**

		NMSC		
	MM	**BCC**	**SCC**	**All NMSC**
Average annual number of cases	303	2466	513	3129
Number of patients registered in 1994	309	2471	554	3166
Percentage of all cancers	1.6%	13.1%	2.7%	16.7%
Percentage of all skin cancers	8.8%	71.9%	14.9%	91.2%
Crude incidence rate per 100,000	8.2	66.5	13.8	84.3
Age-standardised rate (Europe) per 100,000	7.6	54.2	10.6	68.1
5-year % relative survival (1991-93)	78%	-	-	99%

Skin cancer is the most common form of cancer in Yorkshire. Over 3000 cases are registered each year compared to approximately 2500 lung and 2000 breast cases. During the period between 1991 and 1996, on average, 300 MM and 3,100 NMSC cases were registered annually (Table above). While MM cases represented less than two percent of all cancers registered in Yorkshire, NMSC represented nearly 17% of all registered cancers.

4.2. CANCER REGISTRATION

4.2.1. Cancer registration in general

Cancer registration is defined as the systematic collection of data concerning the occurrence and characteristics of reportable neoplasms (Jensen *et al*, 1991). Cancer registration is important for both clinical and epidemiological research and for planning and evaluating health services in relation to prevention, diagnosis and treatment of cancer. Data collected by cancer registries are also used for medical audit, monitoring screening programmes, and education. Registry data are also useful for comparing cancer rates between different populations. Population-based cancer registries aim to register every person who is diagnosed with cancer in the population of a defined geographical area.

4.2.2. Cancer registration in Yorkshire

A population-based cancer registry was established in Yorkshire in 1957 with the aim of collecting and analysing data on every new case of cancer amongst the residents of the former Yorkshire Regional Health Authority area. The Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) was formed in 1997 when the former Northern and Yorkshire Cancer Registries were amalgamated.

The old Yorkshire Region had a relatively stable population of 3.6 million. The Region included the area covered by the following Health Authorities: Calderdale and Kirklees; Bradford; Leeds; Wakefield; North Yorkshire; East Riding and South

Humber. Approximately 17,500 cancer cases were registered annually in the catchment area. Cancer data are systematically collected from a variety of data sources, but the primary sources are reports obtained from pathology laboratories. Following notification from the pathology laboratory, registry staff collect further clinical information from the hospital case notes.

Other routine sources of cancer information are radiotherapy clinics, screening services, private hospitals, hospices and death certificates. The Office for National Statistics (ONS) routinely informs cancer registries about cases where cancer was the primary cause of death. Cancer patients that have died of non-malignant causes are identified to the Registries indirectly through the National Health Service Central Register. When the death certificate is the first notification of cancer, additional information is sought from the hospital where the patient died or from the patient's GP in cases where death did not occur in hospital.

Linking the information received from various sources with the information extracted from patient case notes results in what is termed a "complete registration". Such complete registrations usually include the following information; personal details, anatomical site and type of cancer, date of diagnosis, stage of disease at presentation, and treatment and specialist management details. Every new cancer case is assigned a unique cancer registration number. If an individual is registered twice, then their registration numbers are linked to allow the automatic identification of patients with multiple primaries.

4.2.3. Skin cancer registration in the UK

There is substantial variation in skin cancer registration practice in the UK (Maudsley *et al*, 1997) resulting in unreliable comparisons in cancer rates between regions. Real changes in skin cancer incidence cannot, therefore, be estimated with precision (Craven *et al*, 1994).

A survey of cancer registries (Maudsley *et al,* 1997) showed that, at the time of the survey, while all 11 cancer registries in England register patients diagnosed with MM, only three out of eleven record each BCC. The majority of registries record only the first BCC per patient and two registries do not register BCCs at all. Three cancer registries recorded only one SCC for each patient. The NYCRIS and former Yorkshire policy regarding skin cancer registration is to register only the first incidence of BCC per patient, together with all SCCs and MMs.

One of the reasons that some cancer registries have stopped recording BCCs, or record only one BCC per patient, is because of the financial implications of recording numerous lifetime BCCs. In addition, physicians may not request pathological confirmation in cases where patients have had a previous skin cancer of the same histological type. Many NMSCs are, therefore, treated without histological confirmation, and when cancer registration depends primarily on pathology report notification, it is believed that an accurate recording of the true incidence of NMSC is impossible.

Treatment of skin cancer patients in primary care presents a specific problem for cancer registration. Patients treated in hospital clinics have a high likelihood of registration as hospitals regularly inform population-based registries of patients diagnosed with cancer. However, some patients diagnosed and treated in primary care may not have their excised lesions sent to a pathology laboratory (Khorshid SM *et al*, 1998). It is thus very difficult for cancer registries to know of the existence of these cases unless the general practitioner informs them directly.

There are other diagnostic and treatment options that either do not produce samples that are sent to pathology laboratories, or the available sample is not useful for histological analysis, such as cryotherapy and curettage. The result, again, is that a pathology laboratory as a main source of notification is bypassed.

4.2.4. Completeness of cancer registration

The aim of a population-based cancer registry is to register all cancer cases within a defined geographical area. Ascertainment or completeness of registration is defined as the degree to which reportable incident cases of cancer in a specific population are recorded in the registry (Robles *et al*, 1988). For obvious reasons, it is vital that cancer registries aim towards the absolute completeness of registration.

Quantifying the completeness of registration is important for the correct interpretation of registry data. A brief description of the most common methods used to estimate the completeness of population-based cancer registries follows:

The death certificate only (DCO) index quantifies the proportion of patients for whom a death certificate provides the only notification of cancer (Brenner, 1995). The International Agency for Research on Cancer (IARC) routinely uses the DCO index as an indicator of incompleteness when publishing international cancer incidence statistics (Parkin *et al*, 1992). Every cancer registry estimates the proportion of registrations that are DCO registrations. Some registries also monitor the proportion of cases that were first identified by death certificate (DCI) as a further measure to identify problems with routine case ascertainment.

A yearly comparison of site-specific incidence rates is another method that indicates if there are problems with data capture, and consequently the completeness of the register. Any significant change in incidence suggests that there may be problems with case ascertainment as cancer incidence rates change relatively slowly on a year by year basis.

The mortality to incidence ratio is a further routine tool used for assessing completeness. The ratio between the number of cases registered and the number of deaths per site should be fairly stable. Any sudden fluctuations indicate the possibility of problems with completeness.

Another method used to assess completeness is to compare the number of registrations made in a defined period with the number expected, using the incidence rates from a demographically similar population for comparison. This method is used by the IARC to check the consistency of registries that supply data to them.

The capture-recapture method involves two or more independent methods of case ascertainment, comparing registers that, although independent, will overlap (Robles *et al*, 1988). The so-called three-source capture-recapture method includes cases identified from the following primary sources: hospitals, pathology and death certificates. When the standard two-source method is applied, hospital and pathology are treated as one primary source.

The independent case ascertainment method was used in this study to assess the completeness of the Yorkshire skin cancer registry. This method is regarded as the most objective. It involves the comparison of all cases registered by the cancer registry with cases identified by an independent study in the same geographical area and for the same period. It has been widely used to estimate site-specific completeness of a registry (Nwene *et al*, 1982; Alexander *et al*, 1989, Schouten *et al*, 1993; Swerdlow *et al*, 1993; Melia *et al*, 1995; Richards *et al*, 1995; Lucke *et al,* 1997).

4.3. LITERATURE REVIEW

4.3.1. Early studies

There have been a number of published studies that have used cancer registry data to estimate the level of completeness both generally and in relation to skin cancer. One of the first studies in the UK with the aim of estimating completeness of cancer registration was based on skin cancer data for patients treated in Bristol during 1974 (Beadle *et al*, 1982). Data were collected for a part of the Region covered by the South-Western Regional Cancer Registry from pathology laboratories, medical records departments, and some private practitioners. The study found that the Registry figures underestimated the incidence of malignant melanoma by 8-19%, and of non-melanoma skin cancer by 14 -28%.

In the same year, a study was published on the completeness of ascertainment for 11 sites of cancer during the period 1974-1977 in the North-Western Region of England (Nwene *et al*, 1982). In this study, 1955 cases were identified from three hospitals in the Region, a regional cancer centre and an institution involved in cancer control programmes. Collected data were compared with the Registry master file and the level of completeness was estimated to be 94%. Completeness varied with site and source of data. Malignant melanoma was one of the sites with the highest ascertainment rate (over 98%). Benn and colleagues (Benn *et al*, 1982) used the data from the same Registry to estimate the completeness of cancer registration for a different time period. Two methods were applied: first, registration data were compared with cases identified at the regional radiotherapy centre for the period 1972-73 (96% completeness) and second, cases diagnosed during 1974-75 were analysed by time interval from presentation to registration (93% completeness). The latter method was based on the assumption that among cases diagnosed in hospitals, the proportion of unregistered cases that are alive is equal to the proportion of dead cases that are only registered as a result of receiving a death certificate.

4.3.2. General cancer studies

Since the above studies were published, a number of further studies have been carried out with the aim of investigating ascertainment of several common cancers. In the study undertaken by Seddon and colleagues, the overall completeness rate of registration at the Merseyside and Cheshire Cancer Registry was estimated by reviewing all registered cases diagnosed in 1990 and 1991, and employing capture-recapture method (Seddon *et al*, 1997). The overall completeness rate was 59%, although the rate varied from 47% to 92% according to cancer site. The completeness of NMSC was 71%.

In contrast, one study suggested that there is a little variation in the level of under-registration between sites. In the study of completeness and accuracy of lung, skin and cervical cancer registration at the Northern Cancer Registry, 94% of cervical, 96% lung and 97% of skin cancers were registered (Kardara *et al*, 1995). However, while lung and cervical cancer cases were identified from hospital discharge and death data, and bronchoscopy outpatient clinic data for the lung cancer, skin cancer cases were traced only from the histology register. Since skin malignancies, particularly BCC and SCC, are sometimes treated without obtaining histological verification, identifying cases only from this source could only estimate the completeness of registration of histologically confirmed cases.

The level of registration completeness may vary considerably between the regional registries within the UK. A study of over two thousand Hodgkin's disease cases treated in England and Wales during 1970-1984, found that although completeness did not vary considerably by age, sex or time period, variation between the regional cancer registries was significant (Swerdlow *et al*, 1993). While only 72% of cases were registered in the Wessex region, in the Oxford region 100% were registered. The rate for Yorkshire was 88%. The overall completeness of registration in England and Wales was estimated to be 93%. Cases were extracted from the British National Lymphoma Investigation Register that records lymphoma cases directly reported by clinicians. Identified cases were first checked against the national cancer register, and if records were not found the match was sought on the National Health Services Central Register (NHSCR), and finally, in the appropriate regional cancer registry. As the authors state in the paper, because the identified cases were restricted to those seen in hospitals, some caution is needed in extrapolation of the findings to overall level of completeness.

The study undertaken by Villard-Mackintosh et al also found that under-registration varied significantly between cancer registries (Villard-Mackintosh *et al*, 1988). Although the overall level of under-registration was 13%, the proportion of unregistered cases by registry ranged from 2% to 42%. However, the study population was not evenly distributed amongst the cancer registries, and the number of cancers eligible for registration in some registries was very small (between 11 and 24 cases).

Not surprisingly, there has been variation in the level of completeness reported from cancer registries outside the UK. In a survey that included 82 population-based cancer registries in 10 European Community countries, a significant difference in the quality and completeness of cancer registration was found between registries (Coleman *et al*, 1988). Although most cancer registries reported completeness of registration between 90%-95%, eight registries reported the estimated ascertainment to be below 80%, while eleven gave values of 96% or more. Two registries claimed to register virtually 100% of all incident cases. The authors, however, point out that there was evidence of considerable imprecision in the estimates of completeness of registration supplied by the registries involved in this study. The measure of completeness most commonly used by registries was the incidence to mortality ratio combined for all sites.

4.3.3. General practice studies

A small number of studies involved data collection from general practice and investigated the importance of general practices as a data source for cancer registries. One study that involved 52 general practitioners in the Netherlands had an aim to evaluate the role of general practitioners as a source of information for a cancer registry (Berkel, 1990). The main finding of the study was that it is not cost-effective to initiate active cancer registration system among general practitioners, providing that notification of pathology laboratories to the registry is complete. Only one percent of missed cases were diagnosed by the GP only on clinical grounds and not referred, or were referred but not admitted to a hospital or had a biopsy to confirm the clinical diagnosis. Under-registration of 1.3% would occur if GPs did not act as a data source for the registry. A degree of caution is needed in the interpretation of results from this study as the assumption was made that cancer notification from pathology laboratories was complete.

The role of general practitioners as a data source was also assessed in study that investigated the completeness of cancer registration of another cancer registry in the Netherlands (Schouten *et al*, 1993). On the cancer registry database, records were searched for over three hundred cases identified from a centralised database

maintained by general practitioners in 15 practices and containing patients' details and cancer diagnoses. The cancer registry had registered 96% of cases traced from the GP database (excluding basal cell carcinomas that were not registered).

The above studies by Berkel *et al* and Schouten *et al* were conducted in the Netherlands where the organisation of the health and primary care is fairly similar to the UK. Still some degree of caution needs to be exercised in the interpretation of the relevance of these findings to the present study as the cases included were not restricted to skin cancer.

4.3.4. Skin cancer studies

The recent UK studies that specifically investigated completeness of skin cancers are described in the Section 8.7, where their main findings are compared to corresponding findings of this study.

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5 AIMS AND OBJECTIVES

5.1. AIM

To assess the completeness of skin cancer registration in Yorkshire and recommend strategies for improvement of skin cancer registration.

5.2. OBJECTIVES

i) To assess the proportion of skin cancer cases that were successfully registered in 1994;

ii) To estimate the completeness of data capture from the regional pathology laboratories by assessing the proportion of registered skin cancer cases identified in the regional laboratories;

iii) To assess the proportion of registered clinically diagnosed skin cancer cases by matching records of skin cancer patients identified from hospital databases, samples of outpatient dermatology clinic lists and general practice against the Registry database;

iv) To estimate the number of extra cases that missed the registration process;

v) To recommend possible strategies for improvement of skin cancer registration.

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METHODS 6

6.1. INTRODUCTION

Patients diagnosed with skin cancer in 1994 were identified from various independent information sources around the Yorkshire region. Identified cases were then cross-checked against each other and against the NYCRIS database using a matching algorithm specially developed for this purpose. The number of unmatched cases were identified and analysed by the type of information source, Health Authority, NHS Trust and histological type of skin cancer.

6.2. DATA COLLECTION

The four main information sources were: pathology laboratories, general practices, dermatology outpatient clinics, and NHS Trusts' Information Services for information on patients who received inpatient care. It was necessary to develop different strategies for data collection from each of these four sources. Data on all patients diagnosed in 1994 were gathered simultaneously during the study. The year 1994 was chosen because it was the most recent year for which the Registry dataset was considered complete at the commencement of the study.

In total, information on skin cancer patients diagnosed in 1994 was collected from 14 pathology laboratories, 123 general practices, 7 dermatology outpatients' clinics and 16 NHS Trusts.

The following data items were requested for each identified case to facilitate matching against NYCRIS records:

i) *forename, surname, date of birth, diagnosis (essential data items)*

ii) *patients' address and postcode, laboratory number, hospital number, admission date, managing clinician (desirable data items collected if available)*

6.2.1. Identification of skin cancer patients from pathology laboratories

Every pathology laboratory in the region was contacted to establish if they had analysed skin specimens in 1994. This search resulted in a list of 16 pathology laboratories to be included in the data collection process. All these laboratories were approached to determine their method of record keeping, i.e. whether pathology reports were computerised or kept in paper form. The majority of laboratories (13) had computerised pathology records, and were able to download the required data.

Three laboratories (Bradford Royal Infirmary, St James's Hospital, Leeds and Harrogate General Hospital) used paper-based records for samples analysed in 1994. Harrogate General Hospital was able to supply pathology records in paper form for the entire year. These paper records were reviewed, and patients with skin cancer were identified. A search through the manual records of the other two laboratories

was not practically feasible. The yearly workload at both hospitals was so large that the review process would have involved an excessive amount of study time.

Skin cancer patients were thus identified in fourteen out of sixteen regional laboratories that carried out routine histological examination of skin specimens in 1994.

6.2.2. Identification of skin cancer patients from general practice

Seven Family Health Service Authorities (FHSA) covered the entire Yorkshire region. These FHSAs were approached, and information on general practices within their authority was requested, resulting in a database of all 661 practices in the region. A letter was sent to each of these general practices enquiring whether they were willing to release the information on patients diagnosed with skin cancer in their practice during 1994. Informed consent from patients was not obtained because the NYCRIS register already contained information on the majority of these patients. The Local Research Ethics Committee at Leeds General Infirmary agreed with this approach.

In a pilot phase, two groups of 20 general practices were initially approached to identify the difficulties that practices might experience during the data extraction process. Following the completion of this pilot, letters were sent out to all 661 practices in the region. 331 (50.1%) stated their willingness to supply the required information, including 162 that did not have computerised clinical records. All practices that expressed an agreement to participate in the study were then invited to forward data.

Two reminder letters and a telephone call to all practices that had indicated their willingness to send data, resulted in a total of 123 (19%) general practices that forwarded information on patients diagnosed with skin cancer in their practice during 1994.

6.2.3. Identification of skin cancer cases treated as outpatients

Hospital computer systems across the region do not routinely record a diagnosis for patients attending outpatient clinics. It was, therefore, necessary to review the case notes of patients seen at these clinics in order to identify attendees diagnosed with skin cancer.

A review of existing cancer registration data for 1994 indicated that patients with suspected skin cancer were referred by general practitioners to the following clinics: dermatology, general and plastic surgery, oncology, ENT and ophthalmology (for the lesions on the outer ear and eyelid respectively). Nearly half (47%) of all skin cancer cases were referred to dermatology clinics, while 38% of cases were referred to plastic surgery clinics. Skin cancer patients treated at plastic and general surgery clinics can be identified from Patient Administration Systems even if treated as outpatients (see Section 6.2.4). Thus, outpatient data was extracted only from dermatology clinics.

In some hospitals, the number of patients attending dermatology outpatient clinics can be as high as 5000 per year. A pilot survey was, therefore, undertaken in two hospitals (St James's Hospital, Leeds and Airedale Hospital) to estimate the time taken to identify skin cancer patients among the patients who attended outpatient clinics. This pilot indicated that it would not be feasible to survey all hospitals in the Yorkshire region (see appendix table I).

Data on patients who attended dermatology outpatient clinics during a one month period in either May or September of 1994 were extracted from seven hospitals.

Patients who were under the age of 16 in 1994, and patients who were of Asian origin were excluded, as the likelihood of skin cancers in these groups is very low. In total, 1,617 case notes were reviewed in seven hospitals. One hundred and ninety two patients with MM and NMSC were identified.

6.2.4. Identification of skin cancer cases treated as inpatients

Skin cancer patients who received inpatient care were identified through computerised registers (Patients Administration System (PAS)) that exist in each of the NHS Trusts in Yorkshire. Details of patients who had minor surgery, such as removal of skin lesions at plastic and general surgery outpatients' clinics, are also included in these registers as any surgical procedure done in such outpatient clinics is classified as an inpatient episode and recorded. This also applies to medical oncology patients who attended for chemotherapy. Surgical procedures carried out in dermatology outpatient clinics are, however, not recorded on the PAS systems and this necessitated the outpatient clinic survey mentioned above.

There are seventeen NHS Trusts in Yorkshire. Clinical Information Services in each of the Trusts were approached and information was requested on patients treated for skin cancer as inpatients or in the plastic and general surgery clinics within their Trust in 1994. A download of those cases was received from sixteen NHS Trusts, with only one (Northallerton NHS Trust) unable to forward data despite repeated requests.

6.3. CASE MATCHING

Initially all records from all sources were checked and then combined together to form a single master file (7,609 records). This file contained duplicates that were initially identified by matching all the records against each other using the three key identifying fields: Forename, Surname and Date of Birth. These exact matches were marked and distinct single individuals formed a new file of presumptive unique cases. The master file was again matched against itself using all combinations of pairs of identifiers to produce partial matches – matches which were exact in respect of two identifiers with variation in the third. These partial matches were reviewed manually and the reviewer marked whether the source records were for the same individual. The result of this stage of the matching process was a refined list of unique individuals (6,120 records). This list could now be matched against the entire cancer registry database regardless of diagnosis or year. Matching was initially based on exact Surname, exact Forename and exact Date of Birth. Further matching was carried out using combinations of pairs of identifiers as before. The registry site, type and year were attached to each resultant matched record. Each potential match was ranked according to its priority. Highest priority was assigned to exact matches on identifiers and a skin site, lower priorities for variations. All potential matches were manually reviewed and either assigned to a single registry record or categorised as unmatched.

6.4. ANALYSIS

Estimates were made of the proportions of cases from each source of data that were found in the cancer registry. The first estimates that are given are simply the number of cases matched in the registry divided by the total number in each data source, for MM and NMSC separately. A number of complications arise in this analysis. Firstly, the source and registry diagnoses did not always agree. In these cases, the registry diagnosis was taken as likely to be more accurate and is the diagnosis reported in the analyses. Secondly, cases found in the source records for 1994 frequently matched registrations for years other than 1994 in the registry. There are several reasons why matches on other years might occur (see below) but, in general, no grounds for regarding them as anything other than valid.

Estimates were also made of the proportions of each of the inpatient, outpatient and GP sources that had matched records in the pathology source data. The study did not include all pathology laboratories, so the crude estimates of these proportions would be underestimates. In addition, the estimates were likely to be lowered because the searches of the pathology records were for the same time period (1994) as the other searches (the other information sources, especially outpatient and GP), were likely to include patients who were diagnosed in previous years and so would not have a 1994 pathology record. The earlier pathology records would, however, have been available to the cancer registry. It was thus decided that a better estimate of the proportions would be derived by assuming that all known pathologically verified cases on the cancer registry database had a pathology record. Hence these cases were added to those from the pathology sources to determine the proportions of inpatient, outpatient and GP records with matching pathology records.

7 RESULTS

7.1. DESCRIPTION OF THE SAMPLE

7.1.1. Identified Cases by Type of Source

Table 1a and 1b show the number of cases of skin cancer identified from each information source. It is important to emphasise that these proportions only represent the information available to the study and they do not indicate real availability. A total of 7,609 patient records that reported a diagnosis of skin cancer in the Yorkshire region for 1994 were identified from all sources (Table 1a). Some of these cases were, however, identified from more than one source. Unduplicated records totalled 6,120 (Table 1b).

Half (51%) of all cases identified by this study originated from regional pathology laboratory records. NHS Trust Information Services were the second largest source of cases (39%). These patients were usually treated as inpatients. Ten percent of all cases were identified from a combination of a sample of general practices in the region, and by a review of a sample of outpatient case notes.

Data were collected from fourteen out of sixteen pathology laboratories across the region. Pathology laboratories based at Bradford Royal Infirmary and St James's Hospital in Leeds were not included for reasons explained in the Methods Section (Section 6.2.1). The number of identified cases varied between laboratories. The highest number of cases were reported from Castle Hill Hospital laboratory in Hull (n=822) and the lowest number from the Friarage Hospital laboratory, Northallerton (n=29). A breakdown of figures by individual laboratories is in the Appendix (section 9.2.1).

Patients, who received inpatient care for skin cancer during 1994, represent 39% of all identified cases. Skin cancer cases were identified in all trusts across the region, with the exception of Northallerton NHS Trust (Section 6.2.4). There were five regional Trusts that reported less than 10 cases of skin malignancy during 1994, while several Trusts reported hundreds of diagnosed cases in the same period (Appendix, Section 9.2.1).

A review of over 1600 case notes of patients seen at dermatology outpatients' clinics in seven regional hospitals during a one month period in 1994 revealed 192 (3%) diagnosed with skin malignancies.

Out of a total of 661 general practices in Yorkshire, 123 practices identified 565 cases. More detailed information about case ascertainment from GP practices is presented in the Methods Section (Section 6.2.2).

A large number of cases were identified by one source only. For example, 42% of all unique cases were identified only from pathology laboratories, and 29% only through inpatient records. Amongst cases identified by more than one type of source, the majority were found in both pathology and inpatient sources (17%, n=1,032 cases). This was to be expected given the relative availability of information from the different sources.

Sixty-six percent of all cases identified from pathology reports were single source cases, i.e. they were not found in any other information source (Table 1b, column

four). Sixty percent of all inpatient cases and 48% of both outpatient and GP cases were also single source cases. A proportion of these cases may have had histological confirmation at Bradford Royal Infirmary or St James's in Leeds, thus lowering the apparent rate of cases also identified in pathology reports in these districts.

▼ **Table 1a. Cases identified by information source**

Source	Number of cases	*% of Total*
All Pathology	3,853	***51%***
All Inpatient	2,999	***39%***
All Outpatient	192	***3%***
All GP	565	***7%***
Total	**7,609**	***100%***

▼ **Table 1b. Unique cases identified by information source**

Source	Number of cases	*% of Total*	% of all cases identified in source
Pathology only	2,546	***42%***	66%
Inpatient only	1,799	***29%***	60%
Outpatient only	93	***2%***	48%
GP only	272	***4%***	48%
Pathology & Inpatient	1,032	***17%***	
Pathology & Outpatient	54	***1%***	
Pathology & GP	147	***2%***	
Inpatient & Outpatient	12	***0.1%***	
Inpatient & GP	90	***1%***	
Outpatient & GP	-	**-**	
P+I+O	19	***0.3%***	
P+I+G	42	***0.7%***	
P+O+G	9	***0.1%***	
I+O+G	1	***0.1%***	
P+I+O+G	4	***0.1%***	
All	**6,120**	***100%***	

7.1.2. Identified Cases by District and Type of Source

Table 2a below shows the number and proportion of patients identified in each of the seven former District Health Authorities. Just under a quarter of all cases were identified in North Yorkshire. This is the largest district in Yorkshire and has the second largest population after Leeds. The East Riding, with 18% of cases, was the second largest district, and Leeds the third with 15%.

The proportion of cases identified in each district does not, however, reflect a true picture of the number of skin cancers diagnosed in that district. As mentioned above, data from pathology laboratories in Bradford (Bradford Royal Infirmary) and Leeds (St James's Hospital), and inpatient data from Northallerton NHS Trust (North Yorkshire) were not available. In addition, outpatient data was collected from only a small sample of seven regional dermatology outpatient clinics, and only one fifth of all general practices in the region.

▼ **Table 2a. Cases identified by source and district**

Source District	Pathology	In-patients	Out-Patients	GP	Total	*% of Total*
Bradford	183	679	22	132	1,016	***13.3%***
West Yorkshire	446	29	79	90	644	***8.5%***
East Yorkshire	822	525	0	20	1,367	***18.0%***
South Humber	499	89	-	53	641	***8.4%***
Leeds	505	578	11	58	1,152	***15.1%***
Wakefield	474	441	-	24	939	***12.3%***
North Yorkshire	924	658	80	188	1,850	***24.3%***
Total	**3,853**	**2,999**	**192**	**565**	**7,609**	
% of Total	***50.6%***	***39.4%***	***2.5%***	***7.4%***		

Tables 2b and 2c below show the number and proportion of cases identified in each district by type of information source and by histological type of cancer. A total of

643 MM records and 6,820 NMSC records were identified in all sources. The information received from laboratories, outpatient clinics and general practices discriminate between basal and squamous cell carcinoma. It was not, however, possible to differentiate between these two types of NMSC from the data received from inpatient sources, as the Patient Administration System used by the NHS has only one diagnostic code for all type of NMSC. Therefore, NMSC inpatient data included both BCC and SCC, and, possibly, some rarer forms of cutaneous malignancy.

Tables 2a, 2b and 2c include only a single record per patient if the same patient was identified more than once in the same information source within one district. If multiple records for the same patient were identified in different districts or through different information sources in the same district then all records for that patient are included in these tables.

▼ **Table 2b. Cases identified by information source and district, MM cases only**

Source District	Pathology	Inpatients	Out-Patients	GP	Total	*% of Total*
Bradford	20	66	0	9	95	***14.8%***
West Yorkshire	30	8	9	14	61	***9.5%***
East Yorkshire	65	58	0	3	126	***19.6%***
South Humber	23	13	-	2	38	***5.9%***
Leeds	25	73	0	7	105	***16.3%***
Wakefield	27	45	-	1	73	***11.4%***
North Yorkshire	65	48	7	25	145	***22.6%***
Total	**255**	**311**	**16**	**61**	**643**	
% of Total	***39.7***	***48.4***	***2.5***	***9.5***		**100%**

▼ **Table 2c. Cases identified by information source and district, NMSC cases only**

Source District	Pathology		In-patients	Out-Patients*		GP		Total	*% of All*
	BCC	SCC	BCC & SCC	BCC	SCC	BCC	SCC		
Bradford	130	31	573	14	4	99	20	871	***12.8%***
West Yorkshire	370	44	21	49	18	63	12	577	***8.5%***
East Yorkshire	622	135	467	0	0	12	5	1241	***18.2%***
South Humber	381	94	76	-	-	46	5	602	***8.8%***
Leeds	390	67	498	7	2	47	4	1015	***14.9%***
Wakefield	396	50	352	-	-	19	3	820	***12.0%***
North Yorkshire	712	146	610	46	17	143	20	1694	***24.8%***
Total	**3001**	**567**	**2597**	**116**	**41**	**429**	**69**	**6820**	
% of Total	***44***	***8.3***	***38.1***	***1.7***	***0.6***	***6.3***	***1.0***		***100%***

*In-situ cases are not included in tables 2b and 2c

** All identified MM and NMSC records are included in the above tables. For criteria on how the source diagnosis matches the registry diagnosis, please see table 7.

7.1.3. Identified Cases by Skin Cancer Type, Sex and Age

Table 3 below shows the number of cases identified by type of cancer, sex and age. Comparing all histological types in both sexes, there were proportionally more MM cases identified in females (10%) than in males (7%). Proportionally more SCC cases were, however, identified amongst males (12%) than amongst females (9%). This follows a general pattern that exists for skin cancer in Yorkshire and nationally where female incidence rates for MM are higher than those for males. In contrast, the risk of developing NMSC is greater in men than in women. Just over half of all identified cases (54%) were aged between 60 and 79 years, while only four percent were identified under the age of forty years.

▼ **Table 3. Cases identified by type of cancer, sex and age**

Sex	Type	Age					Total	
		<40	40-59	60-79	80+	Not known	No.	%
Female	MM	68	111	93	25	-	297	***10%***
	BCC	51	338	852	420	5	1,666	***54%***
	SCC	6	23	135	108	1	273	***9%***
	Either BCC or SCC*	29	135	365	237	-	766	***25%***
	In-situ	3	8	46	28	-	85	***3%***
	All	**157**	**615**	**1,491**	**818**	**6**	**3,087**	
Male	MM	31	68	86	19	-	204	***7%***
	BCC	38	348	1001	258	6	1,651	***55%***
	SCC	4	26	239	106	1	376	***12%***
	Either BCC or SCC*	32	114	449	153	-	748	***25%***
	In-situ	-	15	25	8	-	48	***2%***
	All	**105**	**571**	**1,800**	**544**	**7**	**3,027**	
Not known sex				3	2	1	6	
Total	**No.**	**262**	**1,186**	**3,294**	**1,364**	**14**	**6,120**	
	%	***4%***	***19%***	***54%***	***22%***	***0.2%***		

* Inpatient data did not differentiate between BCC and SCC

** Only one record per patient included.

7.2. CASE-MATCHING RESULTS

Table 4 below shows the number of cases, by the type of information source, that were matched with a case on the NYCRIS database. From a total number of 7,609 records found from all four sources, 6,523 (85.7%) had a matching record on the registry database. Cases identified in general practice had the lowest matching rate (71%), while nearly 90% of inpatient cases were matched.

Table 4 also shows the total number of unique cases identified that were matched to the NYCRIS database by data source. 83.5% of 6,120 unique cases were registered. The proportion of matched cases was highest amongst cases that were identified by more than one source. Those cases that were identified by 'GP only' had the lowest rate of matching to the NYCRIS database (48.9%).

There were 62.8% of all identified cases that had a matching record with 1994 as the year of diagnosis. The majority of identified cases are BCCs (see Sections 7.1.2 and 7.1.3), which are commonly recurrent. The NYCRIS policy regarding the registration of BCC was to register only the first incidence in any patient. If a patient had BCC in 1994 and had the same type of skin cancer registered before 1994, it would not be re-registered. Some identified cases with BCC in 1994 were, therefore, matched with records on the NYCRIS database from patients with a BCC diagnosis date prior to 1994. It is also possible that some records received from outpatient and GP sources resulted from follow-up procedures for skin cancers with which patients had been initially diagnosed in previous years.

The proportion of 1994 matches, categorised by type of information source, followed the same pattern as the total proportion of matched cases. Multisource cases had proportionally more 1994 matches with the NYCRIS database. Single source cases from GP sources only had a low rate of matching (34%). The lowest proportion of 1994 matches was, however, in the outpatient only group (10%).

▼ **Table 4. Cases identified by source matched to the NYCRIS database**

Source	No. identified	No. matched	No. un-matched	% *matched*	No. of 1994 matches*	No. of other than 1994 matches	% of 1994 matches
All Pathology	3,853	3,274	579	***85.0%***	2,242	1,032	***68.5%***
All Inpatient	2,999	2,680	319	***89.4%***	1,521	1,159	***56.8%***
All Outpatient	192	168	24	***87.5%***	97	71	***57.7%***
All GP	565	401	164	***71.0%***	236	165	***58.8%***
Total	**7,609**	**6,523**	**1,086**	***85.7%***	**4,096**	**2,427**	***62.8%***
Unique cases only							
Pathology only	2,546	2,036	510	***80.0%***	1,317	634	***68.5%***
Inpatient only	1,799	1,536	263	***85.4%***	624	782	***44.4%***
Outpatient only	93	75	18	***80.6%***	5	43	***10.4%***
GP only	272	133	139	***48.9%***	39	76	***33.9%***
Pathology & Inpatient	1,032	985	47	***95.4%***	675	281	***70.6%***
Pathology & Outpatient	54	50	4	***92.6%***	39	8	***83.0%***
Pathology & GP	147	130	17	***88.4%***	83	42	***66.4%***
Inpatient & Outpatient	12	11	1	***91.7%***	9	1	***90.0%***
Inpatient & GP	90	84	6	***93.3%***	54	24	***69.2%***
Outpatient & GP	-	-	-	**-**	-	-	**-**
P+I+O	19	19	0	***100%***	14	3	***82.4%***
P+I+G	42	41	1	***97.6%***	35	6	***85.4%***
P+O+G	9	9	0	***100%***	7	2	***77.8%***
I+O+G	1	0	1	***0%***	-		**-**
P+I+O+G	4	4	0	***100%***	3	1	***75.0%***
All	**6,120**	**5,113**	**1,007**	***83.5%***	**2,904**	**1,903**	***60.4%***

* Some matched cases did not have a date of diagnosis on the NYCRIS database. As a result, the "No. of 1994 matches" and the "No. of other than 1994 matches" does not equal the overall number of matched cases.

7.2.1. Cases with Matching Registry Records by Type of Source and Skin Cancer Type

Table 5 below shows the number of cases identified by the type of information source and type of cancer matched to the NYCRIS database. Generally, there was no difference between the proportion of cases matched with MM, NMSC and in-situ cases. Overall, cases identified in general practice had a lower percentage of matched MM and NMSC cases (70.5% and 70.7% respectively) than cases of the same histology found in the other three types of sources. "GP only" cases had the lowest proportion of matched cases (48.9%) as compared to the other groups.

▼ **Table 5. Matched cases by source and cancer type**

Source	Skin Cancer Type							
		MM		NMSC		In-situ		Total
All Pathology	230	***90.2%***	3,018	***84.6%***	26	***86.7%***	3,274	***85.0%***
All Inpatient	285	***91.6%***	2,314	***89.1%***	81	***89.0%***	2,680	***89.4%***
All Outpatient	13	***81.3%***	139	***88.5%***	16	***84.2%***	168	***87.5%***
All GP	43	***70.5%***	352	***70.7%***	6	***100%***	401	***71.0%***
Total	571	***88.8%***	5,823	***85.4%***	129	***88.4%***	6,523	***85.7%***
Unique cases only								
Pathology only	121	***88.3%***	1,896	***79.5%***	19	***82.6%***	2,036	***80.0%***
Inpatient only	176	***90.3%***	1,292	***84.7%***	68	***87.2%***	1,536	***85.4%***
Outpatient only	9	***75.0%***	51	***81.0%***	15	***83.3%***	75	***80.6%***
GP only	13	***44.8%***	119	***49.2%***	1	***100%***	133	***48.9%***
Pathology & Inpatient	87	***92.6%***	891	***95.7%***	7	***100%***	985	***95.4%***
Pathology & Outpatient	-	**-**	50	***92.6%***	-	**-**	50	***92.6%***
Pathology & GP	10	***83.3%***	120	***88.9%***	-	**-**	130	***88.4%***
Inpatient & Outpatient	2	***100%***	8	***88.9%***	1	***100%***	11	***91.7%***
Inpatient & GP	9	***100%***	70	***92.1%***	5	***100%***	84	***93.3%***
Outpatient & GP	-	**-**	-	**-**	-	**-**	-	**-**
P+I+O	1	***100%***	18	***100%***	-	**-**	19	***100%***
P+I+G	10	***100%***	31	***96.9%***	-	**-**	41	***97.6%***
P+O+G	1	***100%***	8	***100%***	-	**-**	9	***100%***
I+O+G	-	**-**	0	***0%***	-	**-**	0	***0%***
P+I+O+G	-	**-**	4	***100%***	-	**-**	4	***100%***
Total	439	***87.5%****	4,558	***83.1%***	116	***87.2%***	5,113	***83.5%***

* No. is number of matched cases and % is percentage of matched cases
* * 87.45% rounded to 87% in the executive summary

7.2.2. Cases with Matching Registry Records by Type of Skin Cancer and Age

Table 6 below shows the number of cases that had a match on the Registry database by type of skin cancer and age. The proportion of matched cases was affected by age. The chance of being registered is lower for those under 40 years (72.9%) as compared with the other age groups (83.5% average). Cases with BCCs had the lowest proportion of matches (81.3%) with the registry database.

▼ **Table 6. Cases matched by type of cancer and age**

Type	Age									
	<40		40-59		60-79		80+		All	
MM	78	78.8%	152	84.1%	168	93.9%	41	93.2%	439	87.6%
BCC	67	75.3%	553	80.6%	1,542	83.2%	535	78.9%	2,697	81.3%
SCC	5	50.0%	39	79.6%	333	89.0%	199	93.0%	576	88.8%
Either BCC or SCC*	39	63.9%	201	80.7%	709	87.1%	336	86.2%	1,285	84.9%
In-situ	2	66.7%	19	82.6%	64	90.1%	31	86.1%	116	87.2%
All	191	**72.9%**	964	**81.3%**	2,816	**85.5%**	1,142	**83.7%**	5,113	**83.5%**

* Inpatient data did not differentiate between BCC and SCC

7.2.3. Type of Skin Cancer by Information Source Compared with Type According to Registry

Table 7 below shows, for all the matched cases, a comparison of the diagnosis as recorded in the information sources with that recorded by the Registry. For example, out of 502 unique individual melanoma cases identified from all the information sources, 63 did not have a match on the Registry and of the remainder - 16 were NMSC, 23 in-situ melanoma, three were not skin cancers, and 397 were registered as melanoma.

There were 283 cases (5.5% i.e. 285/5113 matched cases) that had a different diagnosis on the Registry database from that in the original source data (see table). A difference in recorded diagnosis may be the result of coding or typographic errors in either the original information source or the Registry. There were also cases that had two histological types of skin cancer registered. Due to the design of the case-matching process, a case identified from an information source was linked to only one record on the Registry database. Therefore, a second matching diagnosis may still exist in the NYCRIS database. For example, if the information source identified a patient that had both MM and BCC in 1994, and both diagnoses were recorded on the Registry database, only one Registry record would be linked in the matching process. If the MM source record were linked with the BCC Registry record, that case would be counted as the one with a different diagnosis even though the second diagnosis does exist on the NYCRIS database. Because of this, it is likely that less than 5.5% of cases had non-identical diagnoses.

▼ **Table 7. Source and registry diagnosis match by type of cancer**

Source site	Registry site					Source only	Total
	MM	NMSC	In-situ MM	In-situ NMSC	Non-skin**		
MM	397	**16**	**23**	**-**	**3**	63	502
NMSC	**21**	4,345	27	**144**	**21**	927	5,485
In-situ Skin	**6**	**22**	19	**69**	-	17	133
No Source	55	653	82	353	-		1,143
Total	479	5,036	151	566	24	1, 007	7,263

* In bold are cases with a different diagnosis on the registry database (n=283)
** Unspecified cancers and metastatic diseases

7.2.4. Comparison of Cases Found in Source Only, Registry Only and Both by Skin Cancer Type

Table 8 shows the number of cases identified by each information source and by the Registry by type of cancer. 5,113 cases that were identified by this study were also registered in the NYCRIS database. 1,007 cases were identified that did not have a Registry record. The majority (927 = 92% of all unmatched) of these cases were NMSC and this represents 15.1% of all NMSC. Similarly 63 unmatched MM cases were identified representing 11.3% of all MM. A total of 1,143 cases, or 15.7% of all known skin cancer cases, were found only on the Registry database and were not identified from the information sources used in this study. Some of these latter cases will represent data from the two pathology laboratories and the inpatient department whose cases could not be included. In addition, information on skin cancer patients was received from only a sample of outpatient dermatology clinics and general practices. Section 7.3 estimates how many extra cases could be found if all sources in the region were included.

▼ **Table 8. Cases identified by source and registry by type of cancer**

Type	*Source and Registry cases*[1]		*Source Only*[2]		*Registry Only (1994)*[3]		Total
MM	439	***78.8%***	63	***11.3%***	55	***9.9%***	**557**
NMSC	4,558	***74.3%***	927	***15.1%***	653	***10.6%***	**6,138**
In-situ	116	***20.4%***	17	***3.0%***	435	***76.6%***	**568**
Total	**5,113**	***70.4%***	**1,007**	***13.9%***	**1,143**	***15.7%***	**7,263**

[1]identified cases present on the registry database (matched cases)
[2]cases identified only in sources (unmatched cases)
[3]cases not identified in any study sources but known to registry

7.2.5. Registry Cases Not Identified in Information Sources

Table 9 shows, by type of skin cancer and district, the number of confirmed Registry cases that were not identified in any information source used in the study. As described above, data were not received from two pathology laboratories (Leeds and Bradford) and one trust in North Yorkshire. This may explain the large number of cases in North Yorkshire, Leeds and Bradford that remained unidentified by this study.

▼ **Table 9. Registry cases not identified by type of cancer and district of residence**

	Registry District of Residence							
Site	Bradford	W Yorks	E Yorks	S Humber	Leeds	Wakefield	N Yorks	Total
MM	11	4	6	1	18	1	14	55
NMSC	110	69	68	22	163	22	199	653
In-situ MM	2	22	5	2	20	5	26	82
In-situ other	63	32	28	30	74	18	108	353
Total	**186**	**127**	**107**	**55**	**275**	**46**	**347**	**1,143**

7.2.6. Matched Proportions by Type of Information Source and Type of Skin Cancer

As described in Section 7.2.3, a small percentage (5.5%) of cases had a different diagnosis reported by the information source and the Registry. Table 10 shows estimates of the proportion of matched cases from each information source, adjusted for the fact that Registry and source diagnosis were not always identical.

In the case of the "crude" estimate of matched proportions, estimates were calculated assuming the source diagnoses were always correct. The Registry diagnoses are, however, likely to be more accurate due to the more comprehensive registration

process whereby pathology reports are supplemented by case note reviews. Therefore, it is more appropriate to assume that a proportion of source diagnoses were in error. "Adjusted" estimates of the matched proportions assume that, within each source, the misclassification rate of unmatched cases is the same as for matched cases. By comparing the crude and adjusted estimate, it is evident that these estimates are essentially identical.

For the "revised" estimate, a compromise between the source diagnosis and the registry diagnosis is taken. The Registry diagnosis was taken where it was available (i.e. for matched cases). When the Registry diagnosis was not available (i.e. unmatched cases), the source diagnosis was taken. Again the estimates are generally similar.

▼ **Table 10. Adjusted estimate of identified cases by information source and cancer type**

		Crude Estimate	Adjusted Estimate	Revised Estimate
MM	All Path	***90%***	***90%***	***90%***
	All Inpatient	***92%***	***91%***	***91%***
	All Outpatient	***81%***	***81%***	***80%***
	All GP	***71%***	***71%***	***68%***
	Total	***87%***	***87%***	***87%***
NMSC	All Path	***85%***	***85%***	***84%***
	All Inpatient	***89%***	***89%***	***89%***
	All Outpatient	***89%***	***88%***	***87%***
	All GP	***71%***	***71%***	***70%***
	Total	***83%***	***83%***	***83%***

7.2.7. Pathology Matched Proportions by District and Type of Skin Cancer

Table 11 shows the proportion of cases matched to the NYCRIS database found in pathology sources. Only patients diagnosed with invasive malignant melanoma or non-melanoma skin cancer have been included (i.e. in-situ diagnoses have been excluded).

In 1994 all cancer cases were registered with the Yorkshire Cancer Registry (YCR). The YCR was integrated with the Northern Cancer Registry in 1997 to form NYCRIS. It was standard practice at the YCR to receive copies of histology reports directly from each laboratory in the area, and this practice continued after NYCRIS was formed. Since copies of skin cancer reports were sent directly from each regional laboratory, it was expected that cases identified in pathology sources should have a near 100% match with the Registry. However, this study found that 10% of MM and 16% of NMSC cases were not recorded by the Registry. A total of 575 patients found in pathology sources were not registered; 25 MM and 550 NMSC cases.

There was some variation between districts in the matching rates of pathology identified cases. For MM this ranged from 82% to 100% while for NMSC the range was 69% to 93%. See Section 9.2.1 in the Appendix for individual pathology laboratory figures.

▼ **Table 11. Pathology cases with a matching record**

Pathology		Registry			Total
Site	District	Not present	Present	% Present	
MM	**All**	**25**	**226**	***90%***	**251**
	Bradford	3	18	***86%***	21
	W Yorkshire	2	28	***93%***	30
	E Yorkshire	12	53	***82%***	65
	S Humber	0	24	***100%***	24
	Leeds	2	22	***92%***	24
	Wakefield	2	27	***93%***	29
	N Yorkshire	4	54	***93%***	58
NMSC	**All**	**550**	**2,924**	***84%***	**3,474**
	Bradford	11	146	***93%***	157
	W Yorkshire	57	341	***86%***	398
	E Yorkshire	169	570	***77%***	739
	S Humber	43	416	***91%***	459
	Leeds	71	379	***84%***	450
	Wakefield	135	298	***69%***	433
	N Yorkshire	64	774	***92%***	838
Total		**575**	**3,150**	***85%***	**3,725**

7.2.8. Proportion of Patients with Pathology Records

Tables 12a and 12b below show the proportion of identified inpatient, outpatient or GP cases that had a histological confirmation of their diagnosis from a pathology record.

The "Pathology in Source" column represents the proportion of inpatient, outpatient or GP cases identified where a pathology report was also found. However, given that not all pathology laboratories in the region provided data, the low estimates in this column may be misleading. When cases were matched to a histologically confirmed case in the Registry, the number of cases with a pathology record increased significantly, as can be seen in the fourth column. However, this may still underestimate the true histological confirmation rate as it excludes those patients who were missed because of the two excluded laboratories and who did not appear in the registry database.

There were 3 outpatient and 7 GP cases, who were not identified in pathology records and did not have a pathology record on the registry, but were found in the inpatient source information. All of these cases were NMSC. It is very likely that these patients received inpatient care and were then followed up in an outpatient clinic or by their GP. Since it is common practice to send biopsies of hospitalised patients for histological confirmation, these 10 NMSC cases were included as if they had a pathology record.

The column "Pathology in Source or Registry or Inpatients" in table 12b, shows for NMSC the proportion of cases that were identified in pathology sources had a pathology record on the Registry database or were identified as inpatients.

In summary no record of histological confirmation could be found for 11% of MM and 15% of NMSC cases. These figures increased to 28% for both MM and NMSC patients identified in general practice. Either the samples taken from these patients were not sent to laboratory for analysis, or these patients never had skin cancer. It is also possible that GPs suspected malignant lesions and did not update their own records once the pathology report stating the non-malignant nature of the lesion was received.

▼ **Table 12a. Malignant Melanoma**

Source	Total	Pathology in Source		Pathology in Source or Registry		No Pathology Record in Source or Registry	
Pathology	251	N/A		226	(90%)	25	(**10%**)
Inpatients	305	106	(35%)	283	(93%)	22	(**7%**)
Outpatients	15	2	(13%)	12	(80%)	3	(**20%**)
GP	57	23	(40%)	41	(72%)	16	(**28%**)
All	628	131	(21%)	562	(90%)	66	(**11%**)

▼ **Table 12b. Non Melanoma Skin Cancer**

Source	Total	Pathology in Source		Pathology in Source or Registry or Inpatients*		No Pathology Record in Source or Registry	
Pathology	3,474		N/A	2,924	(84%)	550	(**16%**)
Inpatients	2,516	960	(38%)	2,250	(89%)	266	(**11%**)
Outpatients	141	79	(56%)	127	(90%)	14	(**10%**)
GP	479	174	(36%)	347	(72%)	132	(**28%**)
All	6,610	1,213	(18%)	5,638	(85%)	972	(**15%**)

7.3. ESTIMATES OF ADDITIONAL CASES

This section presents estimates of the number of extra cases that might be expected from each data source for 1994. There are a number of assumptions made in calculating these extra case figures. The estimates are based on the matched proportions in Section 7.2.8. No attempt has been made to attach confidence intervals to these estimates, given the non-statistical uncertainties and assumptions made in these data.

Extra cases are presented in a hierarchical fashion, first giving the base number recorded in the Registry, then the estimated additional cases identified from pathology records but not already in the Registry, then further estimated additional cases from inpatient records but not in pathology records or the registry, and then outpatient and GP records.

Pathology cases:

As a full regional dataset from all the relevant pathology laboratories was not available, with information being unobtainable from St. James's, Leeds and Bradford, it was assumed that the average Registry matching rate from the remaining laboratories (90% for MM and 84% for NMSC – Table 11) applied to the region as a whole. These proportions were then applied to the existing number of 1994 histologically confirmed registrations to calculate a total number of estimated registrations and, hence, the estimated additional registrations.

From the study data, 251 patients with MM and 3474 with NMSC were identified from pathology records and, of these, 226 (90.04%) and 2924 (84.17%) respectively had a matched registry record (table 11). Out of the 309 MM and 3,166 NMSC registered cases for 1994, the registry records 304 (98.4%) and 3089 (97.6%) as being histologically verified. Based on the study matching proportions, these latter numbers may be said to represent 90.04% and 84.17% of the true number of histologically verified cases for 1994. This estimated number is, therefore, 304/90.04% = 337.7 (338) for MM and 3089/84.17%= 3670.0 (3670) for NMSC. Subtracting the actual number of registrations from these figures (309 and 3166) gives, after rounding, an estimated 29 additional cases of MM and 504 additional cases of NMSC for 1994.

Inpatient cases:

The numbers of additional cases from inpatient information sources were estimated as inpatient identified cases not matched with a record from the Registry or from the study pathology sources. These numbers were an additional 22 cases of MM and 266 cases of NMSC (Tables 12a and b). But they need to be adjusted downwards because, of the inpatient cases that were matched, only 41% of MM and 45% of NMSC were linked with Registry cases that had a diagnosis year of 1994. After this a final multiplier of 1.06 (17/16) was included to adjust the number upwards, since the inpatient data were received from 16 out of 17 NHS trusts in the region.

The following formula was, therefore, applied and gives rise to an estimated 9 additional cases of MM and 132 cases of NMSC:

*Extra inpatient cases = (total inpatient identified cases * % not present) *%1994*multiplier*

*MM extra inpatient cases = (305*7.21%)*41%*1.06= 9.55 ~ 10 cases*

*NMSC extra inpatient cases = (2516*10.57%)*45%*1.06= 126.8 ~ 127 cases*

Outpatient cases:

The numbers of additional cases from outpatient information sources were estimated as outpatient identified cases not matched with a record from the Registry or from the study pathology or inpatient sources. These numbers were an additional 3 cases of MM and 14 cases of NMSC (Tables 12a and b). However, they need to be adjusted downwards because, of the outpatient cases that were matched, only 10.4% were linked with Registry cases that had a diagnosis year of 1994. After this a final multiplier was included to adjust the number upwards, as the outpatient survey was for only one month and covered only seven outpatient clinics. This study included approximately one third of all outpatient clinics and one twelfth of the yearly caseload. Therefore, the multiplier was taken as 36.

The following formula was, therefore, applied and gives rise to an estimated 11 additional cases of MM and 51 cases of NMSC:

*Extra outpatient cases = (total outpatient identified cases * % not present) *%1994*multiplier*

*MM extra cases outpatient cases = (15*20%)*10.4%*36= 11.23~11 cases*

*NMSC extra outpatient cases = (141*9.93%)*10.4%*36=52.4~ 52 cases*

General practice cases:

The numbers of additional cases from general practice information sources were estimated as general practice identified cases not matched with a record from the Registry or from the study pathology or inpatient sources (no GP identified cases were also identified from outpatient sources). These numbers were an additional 12 cases of MM and 119 cases of NMSC (These are not the figures that appear in Tables 12a and 12b as the % not matched was weighted based on the numbers of GPs in each health authority in the region as a whole, rather than the numbers in each HA in the study). But the additional cases need to be adjusted downwards because, of the general practice cases that were matched, only 40% of MM and 33% of NMSC were linked with Registry cases that had a diagnosis year of 1994. After this a final multiplier of 4.5 was included to adjust the number upwards, since the practices that took part in the study comprised 467 GPs out of 2091 in the region (2091/467=4.47).

An assumption was made that the number of patients is proportional to the number of GPs. The following formula was, therefore, applied and gives rise to an estimated 22 additional cases of MM and 178 cases of NMSC:

*Extra GP cases = (total cases * % not present)*%1994*multiplier*

*MM extra GP cases = (57*21%)*40%*4.5=21.5 ~ 22 cases*

*NMSC extra GP cases = (479*25%)*33%*4.5=177.8 ~178 cases*

Summary

A summary of all these calculations and the impact they have on the additional case projection is provided in Table 13 below.

▼ **Table 13. Estimation of number of additional skin cancer patients for 1994 not initially registered with NYCRIS by information source and skin cancer type.**

Site	Source	Total Cases	% Not Matched	%1994	Multiplier	Estimated Case Number
MM	Registry					**309**
	Pathology		***9.96%***			**+29**
	Inpatient	305	***7.21%***	***41.0%***	1.06	**+10**
	Outpatient	15	***20.00%***	***10.4%***	36	**+11**
	GP	57	***21.00%***	***40.0%***	4.5	**+22**
	Total					**381**
NMSC	Registry					**3,166**
	Pathology		***15.83%***			**+504**
	Inpatient	2516	***10.57%***	***45.0%***	1.06	**+127**
	Outpatient	141	***9.93%***	***10.4%***	36	**+52**
	GP	479	***25.00%***	***33.0%***	4.5	**+178**
	Total					**4,027**

An estimated additional 72 MM and 861 NMSC could be expected to be found if all possible information sources were included. This represents an increase of 23% in MM and 27% in NMSC cases above those already registered. The major component of this increase is information obtained from pathology laboratories representing 40% (29/71) of the additional MM and 59% (504/861) of the additional NMSC. The second most important source was General Practice representing 31% (22/72) of the additional MM and 21% (178/861) of the additional NMSC.

8 DISCUSSION

8.1. STRENGTHS AND LIMITATIONS OF THE STUDY

In 1992 the Health of the Nation document produced by the Department of Health set a target "to halt the year-on-year increase in the incidence of skin cancer by 2005". Incomplete registration of skin cancer cases has been a major obstacle in the accurate monitoring of trends in skin cancer incidence. The purpose of this study was to quantify the level of skin cancer case ascertainment achieved in the former Yorkshire Region in 1994.

The major strength of this study has been the inclusion of outpatient department and general practice records for data collection. Other studies that have investigated the completeness of cancer registration have rarely included these information sources. Data were collected from the entire registry catchment area, and case matching was carried out five years after the study year allowing sufficient time for full data capture.

Although the study design has the above strengths, some limitations have to be taken into account when the findings are interpreted.

First inpatient data from one NHS trust and pathology data from two regional laboratories were not received. In addition, only a sample of general practices (22%) and a very small sample of dermatology outpatients (one third of all outpatient clinics for a period of one month only) were included in the study. There was not, therefore, full ascertainment from any of the four information sources (i.e. pathology, inpatients, outpatients, general practice) available. The number of additional skin cancer cases that would have been expected, if all information sources were fully searched, could be estimated (Section 7.3) but this involved making assumptions about the equivalence of a large amount of missing data.

Second, private hospitals were not included in the study. Although it was our intention at the beginning of the study to include hospitals in the private sector, most of the fifteen hospitals that were approached were unable to provide data. This is because some hospitals did not have computerised morbidity records for 1994 or they required that patient consent be obtained before permitting any data release. Obtaining individual patient consent was not considered feasible because of the large numbers involved and the time limitations of this study. Private hospitals rarely have their own pathology service but use the local NHS laboratory. Specimens from private patients that were sent to NHS laboratories should, therefore, have been routinely identified from the pathology notifications as these data contained information about both NHS and private patients.

Third, it was not feasible to check the residence status of cases identified in areas on the border of the Yorkshire region. Therefore, it is possible that some of the identified cases that were not registered may have actually been resident in the Trent or North-West Cancer Registry catchment areas, but treated in one of the Yorkshire hospitals. The ascertainment rate might actually be higher than estimated as a result. However, the same issue is not true for the former Northern region because all unregistered cases were checked against the records of the Northern region that exist on the NYCRIS database.

This study was of skin malignancies only. Skin cancers, particularly non-melanoma skin cancers, are not representative of all cancers because of the unusual treatment patterns that are specific for this type of cancer. It should not, therefore, be assumed that the reported level of under-registration for skin cancers would necessarily apply to other sites of cancer. However, the registration completeness of other cancers in Yorkshire is an issue that needs investigation considering the fact that this study identified incomplete data capture from the regional pathology laboratories (Section 7.2.7). Pathology laboratories are the main sources of notification about cancer cases and, therefore, incomplete case ascertainment from these sources represents a potential for under-registration of other cancers as well.

8.2. COMPLETENESS OF REGISTRATION

The overall estimate for the proportion of identified skin cancer cases being registered was 87% for MM and 83% for NMSC skin cancer (Table 5). These percentages were based on the number of identified cases, from all four sources of information that were matched against a corresponding record in the Registry database. These figures do not relate solely to the study year of 1994. Although information was requested specifically for this year, because of the different organisation of dates within information systems (especially in hospital PAS systems), data were supplied about patients with Registry diagnosis dates a number of years either side of 1994. Although it is possible to identify which of the matched cases related to a 1994 registration, it was obviously impossible to do this for unmatched cases.

There is some variation between the four information sources in the proportion of identified skin cancer cases who were successfully registered and, in particular, patient information obtained from general practice was the least likely (71%) to be registered. Only half of all patients identified only by general practice (and no other source) were registered. The case ascertainment rate was consistently increased for cases identified via multiple data sources. All but two of 75 cases that were found in three or more information sources had a matched record in the Registry database (Table 4).

Considering just the pathology laboratory derived information, some 10% of identified MM cases and 16% of NMSC were unregistered. This most likely represents a failure to report information to the Registry. The difference in registration completeness between MM and NMSC patients derived from pathology information was statistically significant (95% confidence intervals 86-93% for MM and 83-85% for NMSC) and suggests that the failure to report is more of a problem for NMSC. Tables 1 and 2 in the Appendix show that there was considerable variation between the individual Trusts and Health Authority districts in terms of the matching rate for pathology information. Some show relatively low matching rates for both MM and NMSC while others show low rates for one type and not the other. This would indicate that the problems experienced in reporting information are not uniform to all pathology laboratories.

8.3. HISTOLOGICAL CONFIRMATION

Apart from the complete capture from pathology laboratory information of all histologically confirmed cases, this study has also identified a problem of an absence of such confirmation for a substantial proportion of cases. This directly leads to additional under-registration when pathology laboratories are the main routine source of notification.

In particular, patients diagnosed and treated in general practice for skin cancer frequently did not have histological confirmation of their diagnosis. Pathology records could not be traced for nearly a third of all such patients with both MM and NMSC (Tables 12a and 12b). Even though data from two regional laboratories were unavailable, registered cases were counted as histologically verified when a pathology record was found on the registry database. There is, therefore, only a relatively small possibility that GP cases without a match on the registry database were histologically confirmed in one of the two excluded laboratories. Also, it is apparent from Table II in the Appendix that the two districts (Bradford and Leeds) for which pathology data were missing, had an above average ratio of registered GP cases. In contrast, a significantly low case-matching rate was found for GP identified cases in two districts (North Yorkshire and Wakefield) where pathology data were available.

Cases identified from general practice had a substantially lower percentage of verified pathology records as compared with hospitalised patients and those identified from outpatient departments. Histological confirmation was missing for 7% of inpatient MM cases compared with 20% and 28% of outpatients and GP patients respectively. The number of identified outpatient MM cases was, however, very small (n=15) and only three did not have a pathology record. In the case of NMSC patients, evidence of histological confirmation could not be found for 11% of inpatient, 10% of outpatient and 28% of GP cases. These percentages represent a significant number of NMSC patients who were treated in hospitals but did not appear to have had histological confirmation of their cancer.

8.4. ESTIMATION OF 1994 REGISTRATIONS

The estimated total number of cases for 1994 was 381 for MM and 4,027 for NMSC in comparison with, respectively, 309 and 3166 actual registrations (Table 13). If these figures were taken as the "true" number of cases in the region, then the overall level of registration completeness would be 81% for MM and 79% for NMSC.

Information for this study was returned from a small proportion of general practices (19%) and, especially, outpatient clinics (approximately 3%). In the estimation of total 1994 registrations, it had to be assumed that the relative proportions of registered and unregistered skin cancers in the missing general practices and outpatient clinics would be the same as in those that provided data. As the general practice information, for both MM and NMSC, and the outpatient information for MM, identifies patients with a higher than average likelihood of not being registered, this has a particularly disproportionate effect in the estimation of additional missing cases. It is unknown to what extent the general practices and outpatient clinics that provided data would represent a biased subset of the whole. Bias may be a particular problem for the general practice information, responding practices having systematic differences among their patients compared with non-responding practices. Although the selection of outpatient clinics to review was made by the study team and would be less likely to be biased, the fact that only 3% of all clinics could be surveyed means that there will be considerable uncertainty in extrapolating from these to the other 97%.

Removal of the general practice and outpatient contribution to the overall estimation from 1994 resulted in a total number of cases of 348 for MM and 3797 for NMSC and registration completeness rates of 89% and 83% respectively. The completeness rates including & excluding the general practice and outpatient figures (81-89% for MM and 79-83% for NMSC) are likely to represent the upper and lower estimates for completeness. The effect of these estimated additional cases on the crude incidence rates for Yorkshire would be to increase the reported 1989-93 rates of 7.5 per 100,000

per annum for MM and 72.9 per 100,000 per annum for NMSC (YCO, 1996) to 8.7-9.3 and 88.9-92.2 per 100,000 per annum respectively.

8.5. IMPROVING ASCERTAINMENT

The figures in Table 13 show that, for non-melanoma skin cancer, if there are an estimated 4027 cases regionally, our data indicate that 91% would be captured by complete reporting of all the histologically confirmed cases from pathology laboratories. Inclusion of inpatient, outpatient and general practice information would result in a further 3%, 2% and 4% of the total respectively a combined addition of 357 patients. For malignant melanoma, the proportions are very similar - 89% of all cases could be captured from pathology with a further 2%, 3% and 6% from the other three sources respectively a combined addition of 43 patients.

In terms of an overall cost effectiveness, complete capturing of pathology information would appear to result in registration of approximately 90% of both malignant melanoma and non-melanoma skin cancer. Each of the other sources of information would increase the registration rate by a few percentage points but the only easily accessible additional data source, inpatient information from hospital PAS records would only increase completeness by 2 to 3%. Numerically the most important additional information source, especially for non-melanoma skin cancer, would be general practice but currently there is no electronic mechanism in place for routinely capturing this information. Clearly the best solution would be to increase the histological confirmation rate for skin cancer so that it approaches 100%.

It might be suggested that capturing PAS information may be a better primary source of routine capture of skin cancer cases than using pathology laboratory information. Indeed some registries do make use of PAS in preference to pathology for general cancer registration. This study has, however, identified several irregularities in the morbidity data recorded on PAS. As is evident from Table I in the Appendix, only a fraction of skin cancer cases that were treated in hospitals are recorded in the PAS system. For example, 183 skin cancer patients were identified by Airedale NHS Trust pathology laboratory, whilst only one patient was recorded on their PAS system. In Grimsby, of 296 pathology cases identified by the pathology laboratory, only 11 had a record on PAS. These numbers indicate shortcomings in the recording of data on PAS at least in 1994. Private hospitals and GPs send specimens to local NHS pathology laboratories and these patients would not be expected to be recorded in PAS but this can not be an explanation for the large discrepancies between the number of cases in pathology databases and PAS. The under-recording of cases on PAS may be the result of irregularities in diagnostic coding on the system or poorly developed data exchange links between laboratory and information departments. It is unclear whether the deficiencies in the use of PAS information are specific for skin cancer as a result of the relatively unusual treatment pattern. Despite these problems, the use of PAS together with pathology information did increase the matching rate in comparison with either source alone (Table 5) and thus it might be considered as a useful and readily available ancillary source.

The problems outlined above with PAS were observed during the study year (1994). The computer systems in NHS hospitals are systematically reviewed and upgraded and it is reasonable to assume that patient information recorded on PAS has improved since. It would be, however, essential to crosscheck PAS records against pathology databases before any great reliance is placed upon them.

In 1994, three out of sixteen regional laboratories did not have computerised pathology records and, since then, the remaining three laboratories have established

electronic databases. The increased availability of computerised information on cancer patients, especially within pathology laboratories, combined with access to the NHSnet forms a basis for the development of electronic data collection by cancer registries. Appropriate networked connections could now be established, at least in principle, with computerised systems within all pathology laboratories. Such data capture has already been developed in several UK cancer registries, for example the Trent and Wessex Cancer Registries (Automated Data Collection in Cancer Registration, IACR, Black). The multiplicity of pathology systems available means, however, that it is difficult to devise generic protocols for communication between laboratories and registries. Such a data capture process should however provide a platform for cancer registration. Our study shows that reliable and complete ascertainment of pathological diagnoses would enable registration information to be obtained on at least 90% of all skin cancers.

While this report was being drafted a national Action Programme for Cancer Registration (http://www.doh.gov.uk/cancer/actionprogramme.htm) was published by the Department of Health covering the nine English registries. This recommended that, over the next 3-5 years, all registries should develop strategies to collect a core National Cancer Registry Dataset by electronic transfer from hospital information systems. The dataset is to be determined and defined nationally as part of the Cancer Information Strategy (http://www.doh.gov.uk/cancer/cis.htm) and, *inter alia*, will include standardised site specific pathology details on *pro-forma* developed by the Royal College of Pathologists. Hospital trusts will be responsible for compiling standard datasets for all their cancer patients as part of the development of cancer networks. These changes, when fully implemented, could rectify many of the deficiencies in registration process highlighted in this study.

8.6. QUALITY CONTROL

Our study has demonstrated the benefits of multiple source ascertainment for registration and additional data capture from PAS would improve the overall completeness of registration although only by 2-3%. This may not be viewed as significant especially if the histological confirmation rate for skin cancer could be improved from the levels observed in 1994. However every NHS Trust has a computerised PAS from which cancer patients were identified for this study and linkage with these systems may become necessary anyway for the capture of information about other sites of cancer and for treatment details. Also the figure of 2-3% additional benefit would be increased if, as was the case for 1994, pathology laboratories were not able to provide reports for all their skin cancer patients. Multiple source ascertainment would also not only improve completeness but also the accuracy of information recorded. Indeed the development of multiple electronic links for data exchange should improve the quality of all the information sources as inconsistencies could be investigated and corrected both in the original data source and in the Registry dataset.

Using any electronic data capture for registration could potentially create duplicate records of the same tumour unless effective data linking procedures are also developed. It will be vital, therefore, to develop efficient patient matching algorithms that will have the aim of determining, for each notified case, whether the individual and the cancer are already known to the Registry and/or are identified in a different information source.

Direct linkage of registries with hospital outpatient and general practice systems can not be considered as a short-term objective. Although there is some degree of

computerisation in all outpatient departments, it was not possible to extract sufficiently detailed information from the systems without additional manual searches of clinical notes. Most general practices are also now computerised but an enormous investment would be required to obtain usable information from them on a routine basis. As each practice is unlikely to manage more than 2 or 3 new skin cancers each year, this is unlikely to be cost effective.

8.7. COMPARISON WITH OTHER STUDIES

A substantial under-recording of non-melanoma skin cancers was identified in the study carried out over 6 months during 1988 in the area of South Wales (Roberts, 1990). All clinicians in the relevant specialities and pathologists reported patients that were diagnosed with NMSC during the study period. Based on the number of reported cases, a much higher than expected incidence of NMSC was found the with a crude annual incidence rate of 173.5 per 100,000 as compared to 67.5 which had been estimated based on registry data. The estimated Yorkshire crude NMSC rates are substantially lower, between 88.9 and 92.2 per 100,000 (Section 8.4).

Holme and co-authors used the data extracted from the local skin cancer registry to estimate the incidence rates for non-melanoma skin cancers in South Wales for the 1998 (Holme et al, 2000). Based on the number of BCC and SCC cases registered during the 6-months period in 1998 (n=490), the crude incidence rate for NMSC was estimated at 265 per 100,000 per annum. That is a significant rise in comparison to incidence rate of 173 per 100,000 found in the above study undertaken by Roberts that estimated the NMSC incidence for the same area ten years earlier. The incidence of 265 per 100,000 is almost three times higher than the estimate figure for Yorkshire (88.9-92.2 per 100,000, Section 8.4).

In addition to the above, there have been three more recently published studies in the UK that specifically investigated completeness of skin cancer registration. In the first, the completeness of non-melanoma skin cancer was estimated at the West of Scotland Cancer Registry (Lucke *et al*, 1997). BCC and SCC cases diagnosed and treated in Greater Glasgow during a one month period in 1995 were included (n=111). All dermatologists working in Greater Glasgow were asked to record patients that present to them with either a BCC or a SCC during that time period. The study found that 31% of Basal Cell Carcinoma and 44% of Squamous Cell Carcinoma failed to be included in the registration process at the beginning of 1996. That is a much higher proportion of unmatched NMSC cases than in the Yorkshire region where 17% of identified BCC and SCC cases were unregistered as indicated by our study (Table 5). However, the high proportion of unregistered cases in Glasgow could be partly a result of a short time period between diagnoses and the case-matching process (9 months). This study also showed that, in Glasgow, dermatologists rarely treated skin tumours without obtaining pathological confirmation of diagnosis. Approximately 96% of patients seen by a dermatologist had a biopsy, while the corresponding figure in our study was 89% (Table 12b). There is a possibility that, because the dermatologists were aware of the study, this might have influenced their decision to seek histological confirmation.

The second study was a retrospective survey of MM registration undertaken by the South-Western Regional Cancer Registry (Richards *et al*, 1995). Data were obtained from four NHS hospitals with a computerised histopathology systems within the Bristol and District Health Authority and two private hospitals. It was concluded that the incidence of malignant melanoma was underestimated by 13%. The study period was 1984 to 1993. In the first half of the study period (1984-89), the proportion of

unregistered cases was substantially lower (between 1% and 12%) than in the second half (14-31%). Private hospitals generated a quarter of all unregistered cases.

An under-registration level of 13% suggests that there was no improvement in the ascertainment of the South-Western Regional Cancer Registry compared to a period of ten years earlier. (The study undertaken by Beadle et al showed that, in 1974, the same registry missed 8-19% of malignant melanomas.)

In a study undertaken by Melia et al, four cancer registries that cover seven health districts in England and one in Scotland were included (Melia *et al*, 1995). Information on malignant melanoma cases was collected from four main information sources: pigmented lesion clinics, local melanoma registers based on patients attending dermatology departments in hospital and pathology laboratories. The study period was from 1987 to 1989. The proportion of registered malignant melanomas recorded as histologically confirmed ranged from 89% at one English registry to 99% in Scotland. Of all registered MM cases in Yorkshire for 1994, 98.4% were recorded as histologically confirmed (see section "Estimates of Additional Cases").

A significantly lower proportion of cases diagnosed in England were registered (74%, range from 66% to 88%) comparing to cases diagnosed in Scotland (96%). The corresponding figure for Yorkshire was 88% in 1994 (Table 5).

Of all MM cases, 22% were identified at the information sources alone, 22% were identified by the registries alone and 56% of cases by both (figures in our study for Yorkshire in 1994 were 11%, 10% and 79% respectively, Table 8). The proportion of cases that were identified by the registries alone and were not identified in any of the information sources ranged from 12% to 37% (average 22%). These figures can be compared with the 10% of registered cases not identified in Yorkshire data sources, indicating a more complete coverage of such sources.

8.8. CONCLUSIONS

- Among the 6120 skin cancer cases identified in this study, diagnosed around 1994 among Yorkshire residents, 5113 (84%) were registered with the Cancer Registry - 439 out of 502 (87%) patients with malignant melanoma and 4558 out of 5485 (83%) patients with non-melanoma skin cancer.
- On the basis of extrapolations from these figures, it is estimated that approximately 81% to 89% of all malignant melanoma cases and 78% to 83% of all non-melanoma skin cancer cases diagnosed within the Yorkshire Region in 1994 were successfully registered by the Cancer Registry. The uncertainty is primarily due to the fact that, unlike most other cancers, a significant proportion of skin cancer is diagnosed and treated within hospital outpatient clinics or general practice. It is difficult to estimate with precision the total number of unregistered cases from these sources.
- Adjustment for the above rate of under-reporting would mean that the true regional annual incidence rates for these cancers would be 8.7-9.3 per 100,000 (based on 348-381 cases) for malignant melanoma and 88.9-92.2 per 100,000 (based on 3797-4027 cases) for non-melanoma skin cancer – substantive increases on the reported figures of 7.5 and 72.9 per 100,000 per annum respectively (based on 309 and 3166 actual registrations [YCO, Cancer Statistics]).
- If all patients with skin cancer had histological confirmation of their diagnosis, complete capture of information from pathology laboratories would result in close to 100% registration. This study found that, in 1994, approximately 90% of all

skin cancer patients (both malignant melanoma and non-melanoma skin cancer) had such confirmation and would have been registered if there had been complete capture of information. In practice, an estimated 10% of malignant melanoma patients and 16% of non-melanoma skin cancer patients, who had received histological confirmation, remained unregistered.

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- Hospital inpatient PAS datasets can not be used as a primary information source for skin cancer as, unlike pathology laboratory data, information is not held on patients treated in dermatology outpatient clinics, general practice or private practice. Also discrimination between the two major sub-types of non-melanoma skin cancer is not possible from PAS. The study showed that there were substantial deficiencies in the completeness of recording of skin cancer in PAS even after making allowance for the above. This varied substantially between hospitals.

- Use of PAS datasets, as a supplementary information source to that obtained from pathology laboratories, would further improve completeness by 2-3 %. This figure would increase if there were any problems in the pathology reporting process. Cases reported by both pathology and PAS systems were more likely to be registered than those reported by either source alone.

- The main value of PAS data for skin cancer registration would be to act as a source of quality control information improving the overall accuracy of the skin cancer dataset and indicating any problems in the supply of pathology laboratory information.

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- Information from hospital outpatient clinics could, if systematically captured increase completeness by a further 2-3%. There are, however, no systems in place to capture such information and there is no easy process to identify outpatient managed cases routinely. If all skin cancer cases diagnosed in these clinics are histologically confirmed, they should be identified through pathology laboratories. In 1994, 20% (3 out of 15 cases) of malignant melanoma and 10% of non-melanoma skin cancers managed in outpatient clinics, appeared to have no histological confirmation.

- Skin cancer patients managed in general practice represent the most important source of cases potentially missed by routine registration processes. They are also the most likely to fail to be histologically confirmed. In 1994, 28% (16 out of 57 cases) of malignant melanoma and 28% of non-melanoma skin cancers managed in general practice, appeared to have no histological confirmation. No systems are in place to capture routinely skin cancer diagnoses made within general practice although the development of IT systems within primary care trusts may cause this situation to change in the future. It is particularly important for general practitioners to seek histological confirmation of suspected cancers not only for

cancer registration processes but also as part of the appropriate management strategy for their patients.

- The optimal means for registration of skin cancer patients diagnosed in hospital outpatient clinics or in general practice is currently through pathology laboratories. Improving the capture of these patients is, therefore, dependent on improving the histological confirmation rate. **G**

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- Hospitals within the Yorkshire region appear to experience different problems with respect to the identification and recording of cases**. P**

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. Since cancer incidence rates changes relatively slowly, any oscillation could be a sign of problems with data capture and the completeness of cancer registration

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APPENDIX 9

9.1. MALIGNANT MELANOMA IN GENERAL PRACTICE QA STUDY

As the number of registered cases was significantly lower in general practice, the GPs of all those MM cases identified only by general practice and not present in any other information source and without a matching Registry record (n=16) were re-contacted. Further details were requested, such as the date of diagnosis or the first visit to the GP regarding the MM, the chosen treatment, whether a biopsy was send to a laboratory, and which hospital the patient was referred to (if at all). Further details concerning unregistered NMSC cases were not requested because of the large numbers involved.

Further details were received for 11 of 16 of these unregistered cases. Three were cases of MM apparently treated in a regional hospital, 3 were referred outside the region (to hospitals in the former Northern region), 2 were treated at private hospitals and 3 were suspected MM cases that were determined to be non-malignant lesions after investigation by a pathology laboratory. The eight cases treated in Yorkshire, at private hospitals and in Northern Region NHS hospitals should have be registered given the method of case ascertainment employed by the Registry, and the fact that the Northern and Yorkshire registries were merged in 1997. There is a mutual arrangement between Cancer Registries that when a patient is identified who resides outside of the Registry's own catchment area, the cancer registry that covers the patient's residing area is informed. However, there was no record in the NYCRIS database of the three cases who were first diagnosed in general practice in Yorkshire and subsequently treated in the Northern region.

The above mentioned unregistered cases should all have been registered with the NYCRIS database apart from the three histologically confirmed non-malignant cases that were identified as MM in the GP records. Note that these three mis-recorded GP cases were collected from a single practice, which indicates the lack of precision of computerised morbidity data held in that practice.

9.2. DETAILED TABULATIONS

9.2.1. Cases with Matching Registry Record by Type of Source, District and Trust

Pathology

The number of identified pathology cases varied between laboratories. The highest number of cases was reported by East Yorkshire NHS Trust laboratories (822, 21.8%). The lowest number was found at the Northallerton Health Services Trust laboratories (29, 0.8%).

Eighty-five percent of all pathology cases had matching records on the registry. However, only 31.9% (52/166) of cases from the Pontefract NHS Trust laboratory

were registered. The pathology laboratory that analyses specimens for both East Yorkshire Hospitals NHS Trust and Royal Hull Hospitals NHS Trust, and the laboratory at the Huddersfield Healthcare NHS Trust had lower than average rates of matched cases (77.4%, 74.7%). Laboratories at Dewsbury and York trusts had a very high proportion of registered cases (93.5%, 93.3%).

Inpatients

In total, 2,999 hospitalised cases were identified in 16 Trusts. The number of identified cases varied by Trust. There are five regional Trusts that had less than 10 patients recorded with a diagnosis of skin malignancy in the whole year of 1994, while several Trusts reported hundreds of cases diagnosed in the same period. The wide range in the number of skin cancers identified across the regions is not solely as a result of the size of the region, i.e. the number of hospitals and specialists clinics. Irregularity in the coding of diagnosed cases could also be a possible explanation.

Discounting those sources that identified very low numbers of cases during the study year, inpatient cases at the Calderdale NHS Trust had the lowest percentage of registrations (73.7%). St James's, Pinderfields, Scarborough and York Trusts had percentages of registered cases above the overall percentage of registered inpatient cases.

Outpatients

Cases diagnosed with skin malignancies in outpatient clinics were identified by reviewing the case notes in seven regional hospitals during one-month period in 1994. Over sixteen hundred case notes were reviewed, and 192 cases identified. 87.5% of these cases had a matching case on the registry database.

All

Pontefract Hospitals NHS Trust had the lowest number of matched cases (32.5%). However, this figure is based on pathology data only as outpatient records were not searched, and only 3 inpatients were identified.

Wakefield district as a whole had the lowest percentage of registered patients, largely due to the high number of unmatched cases found in the laboratory at the Pontefract Hospitals NHS Trust.

North Yorkshire district, a district with the highest number of identified skin cancer cases, had the highest proportion of registered patients (91.8%).

▼ **Table I. Matched cases by district and trust**

District	Cases		NHSTrust	Pathology		Inpatients		Outpatients			All (%)	
	No. Identified	% matched		No. Identified	*% matched*	No. identified	*% matched*	**No. reviewed**	No. identified	*% matched*	No. identified	*% matched*
Bradford	884	**87.4%**	Airedale	183	***92.3%***	1	***100%***	**264**	22	***81.8%***	206	***91.3%***
			Bradford Hospitals	-		678	***86.3%***	**-**			67	***86.3%***
West Yorks	554	**86.1%**	Calderdale Healthcare	169	***89.3%***	19	***73.7%***	**400**	35	***91.4%***	223	***88.3%***
			Dewsbury Health Care	119	***97.5%***	7	***85.7%***	**390**	44	***84.1%***	170	***93.5%***
			Huddersfield Healthcare	158	***74.7%***	3	***100%***	**-**			161	***75.2%***
East Yorks	1,347	**82.2%**	East Yorkshire Hospitals	822	***78%***	9	***66.7%***	**55**	0	**-**	831	***77.9%***
			Royal Hull Hospitals		***incl. in the above ****	516	***89.1%***	**-**			516	***89.1%***
South Humber	588	**90.5%**	Scunthorpe & Goole	203	***91.1%***	78	***85.9%***	**-**			281	***89.7%***
			Grimsby Health	296	***91.6%***	11	***81.8%***	**-**			307	***91.2%***
Leeds	1,084	**88.5%**	United Leeds Teaching Hospitals	505	***85.1%***	235	***83.8%***	**33**	8	***75%***	748	***84.6%***
			St James's & Seacroft University Hospitals	-	**-**	343	***94.5%***	**145**	3	***66.7%***	346	***94.2%***
Wakefield	915	**81.7%**	Pinderfields Hospitals	308	***92.2%***	438	***93.4%***	**-**			746	***92.9%***
			Pontefract Hospitals	166	***31.9%***	3	***66.7%***	**-**			169	***32.5%***
North Yorks	1,662	**91.8%**	Northallerton Health Services	29	***89.7%***	-	**-**	**-**			29	***89.7%***
			Scarborough & NE Yorkshire	286	***92.3%***	146	***93. 8%***	**330**	80	***91.3%***	512	***92.6%***
			York Health Services	453	***96.9%***	494	***90.1%***	**-**			947	***93.3%***
			Harrogate Health Care	156	***81.4%***	18	***83.3%***	**-**			174	***81.6%***
All	7,044	**86.9%**		3,853	***85%***	2,999	***89.4%***	**1,617**	192	***87.5%***	7,044	***86.9%***

* Pathology laboratory at the Castle Hill Hospital analyses specimens for two Trusts; East Yorkshire Hospitals NHS Trust and Royal Hull Hospitals NHS Trust.

NB. Trust names reflect those in use during the study year (1994).

General Practice

In total, 565 cases of skin malignancy were found in primary care. 467 GPs work in 123 practices that took part in this study. The total number of GPs in the Yorkshire region is 2,091. On average, just over one (1.2) skin cancer patient per GP was identified.

Overall, 71% of all patients found in general practice were linked with a corresponding case on the registry database. However, 60% of all GP patients from North Yorkshire were not registered, while GP cases in Wakefield had the lowest matching rate (42%) of all districts.

▼ **Table II. Matched cases in general practice**

District	Number of identified cases	Number of GPs' included	Number of identified cases per GP	Number matched cases	% Matched
Bradford	132	87	1.5	102	***77%***
West Yorkshire	90	93	1	76	***84%***
East Yorkshire	20	27	0.7	16	***80%***
South Humber	53	36	1.5	42	***79%***
Leeds	58	69	0.8	43	***74%***
Wakefield	24	29	0.8	10	***42%***
North Yorkshire	188	126	1.5	112	***60%***
Total	**565**	**467**	**1.2**	**401**	***71%***

9.2.2. Matched Proportions by District of Residence, Data Source and Diagnosis

Table III below shows the proportion of matched cases by Registry district of residence, data source and type of cancer. Where it was available (i.e. for matched cases) the registry diagnosis was taken to estimate match proportions. In the case of unmatched cases, the source diagnosis was included.

▼ **Table III. Matched cases by Registry residence, data source and type of cancer**

Type	District	Pathology	Inpatient	Outpatient	GP
MM	**All**	**90%**	**91%**	**80%**	**68%**
	Bradford	86%	92%		88%
	W Yorkshire	93%	89%	75%	75%
	E Yorkshire	82%	91%		100%
	S Humber	100%	87%		100%
	Leeds	92%	93%		67%
	Wakefield	93%	92%		50%
	N Yorkshire	93%	90%	86%	52%
NMSC	**All**	**84%**	**89%**	**87%**	**70%**
	Bradford	93%	85%	82%	75%
	W Yorkshire	86%	75%	86%	85%
	E Yorkshire	77%	88%		75%
	S Humber	91%	84%		77%
	Leeds	84%	89%	80%	74%
	Wakefield	69%	95%		41%
	N Yorkshire	92%	90%	91%	58%

9.2.3. District of Source Compared to District of Residence According to Registry

As evident in Table IV below, there was not an absolute agreement between a district of residence taken from the registry database and district from where patients were identified. In total, 985 (16%) of all matched cases have non-identical districts according to the source data and the registry database. Since source districts represent where patients were treated, it is likely that this variation between residing district and

district where patients received treatment is due to availability of local services. Patients with lesions at difficult sites, particularly the face, living in districts where number of specialists in plastic surgery are limited or non existent, would have been referred to neighbouring district that had plastic surgery services.

▼ **Table IV. Cases residence versus cases record source district**

Source Area	Registry District of Residence							Not matched	Total
	Bradford	Leeds	East Yorks	West Yorks	South Humber	North Yorks	Wakefield		
Bradford	550	**25**		**126**		**124**		191	1,016
W Yorkshire	**6**	**6**		507			**13**	112	644
E Yorkshire		**3**	942	**1**	**100**	**36**		285	1,367
S Humber			**58**		449			134	641
Leeds	**21**	797	**5**	**20**	**1**	**126**	**7**	175	1,152
Wakefield		**87**	**1**	**115**		**19**	490	227	939
North Yorks	**3**	**14**	**65**	**3**		1444		321	1,850
All	580	932	1,071	772	550	1,749	510	1,445	7,609

* In bold are cases with non-identical districts (n=985)

9.3. SURGICAL MANAGEMENT OF SUSPECTED SKIN CANCERS IN GENERAL PRACTICE

The overall number of skin lesions removed by general practitioners has increased over the past decade, particularly since the introduction of the 1990 contract.[1,2] Little is known about how GPs differ in their surgical management of skin cancer. Concerns have been raised concerning GPs' competence with minor surgery,[3,4] and because, in one study, a prior clinical diagnosis of melanoma was only made in 17% of GP excised proven melanomas.[5]

In 1997, as a part of the main study, we undertook a postal questionnaire survey amongst the GPs in the former Yorkshire Regional Health Authority. The aim of this survey was to investigate the surgical management practices of newly diagnosed skin cancers. We investigated GPs' management of skin cancer; whether and how often GPs operate on lesions suspected to be melanoma and non-melanoma skin cancer; and whether differences in management are associated with GPs having specialist skills in dermatology or having a visiting dermatologist in the practice.

Methods and results

The questionnaire was mailed to all GPs in the region (n=2,091 based in 661 practices) and asked whether they operated on lesions they suspected to be either MM or NMSC, how often they did so for NMSC, where they referred skin cancer patients, and whether they were clinical assistants in dermatology or a related surgical specialty. Information on whether the practice had a visiting dermatologist was collected from the practice managers. Fisher's exact tests were performed on contingency tables.

Completed questionnaires were received from 1,167 GPs (55.8%) from 458 practices (69.3%). More than 10% of GPs answered that they operated on lesions they suspected to be MM, and just under a third (31%) operated on suspected NMSC (see table 1). In addition, 5% of GPs referred some of their patients with suspected MM to one of the partners in the practice who had responsibility for all minor surgery on skin lesions, and 10% referred patients with suspected NMSC. GPs with a visiting dermatologist were more likely to perform minor surgery for lesions suspected to be NMSC, and GPs who held clinical assistantships in dermatology or a related surgical specialty were more likely to perform surgery for lesions suspected to be MM or NMSC (table 1). Of those GPs who reported operating on suspected NMSC, 188

(51.4%) stated that they excised 1-6 lesions per year, 82 (22.4%) stated 7-14, 54 (14.7%) stated 15-24, 19 (5.2%) stated 25-34, and 12 (3.3%) stated 35-45 lesions. Ten (2.7%) general practitioners reported removing more than 45 lesions per year.

Discussion

The data show that the number of GPs who reported operating on suspected malignant skin lesions was high, with more than 10% of GPs saying they operated on suspected MM, and just under a third saying they operated on suspected NMSC. The accuracy of clinical recognition of malignant lesions is significantly lower among GPs than among hospital surgeons[3]. In 1991, 36% of lesions excised by GPs were incomplete; and 80% of lesions not recognised by GPs as premalignant or malignant were incompletely removed.[3] Although GP training in minor surgery will have probably improved in the recent years, there still remain potential problems in the management of skin cancers given the extent of GPs' excision of skin lesions; simple arithmetic from these data suggest that GPs may operate on 5000 to 6000 suspected NMSCs annually in the UK. In addition, those who do operate, do so relatively infrequently in comparison to dermatologists who each typically perform 500-600 such procedures per year.

▼ **Table 1. Self-reported surgical behaviour of GPs for melanoma and non-melanoma**

	Number (%) of doctors reporting that they operate on suspected lesions	all GPs	GPs with a visiting dermatologist[a]	GPs who are clinical assistants in dermatology or a related surgical speciality[b]
Melanoma	'On most occasions'	29 (2.5)	1 (1.2)	5 (9.4)
	'On some occasions'	104 (8.9)	7 (8.5)	13 (24.5)
	'Do not operate'	1034 (88.6)	74 (90.2)	35 (66.0)
	Total	**1167 (100.0)**	**82 (100.0)**	**53 (100.0)**
	p (all responses)[c]		*0.232*	*<0.001*
	p (operating vs. not operating)[c]		*0.135*	*<0.001*
Non-melanoma	'On most occasions'	132 (11.3)	8 (9.8)	20 (37.7)
	On some occasions'	234 (20.1)	21 (25.6)	15 (28.3)
	'Do not operate'	800 (68.6)	53 (64.6)	18 (34.0)
	Total	**1166 (100.0)**	**82 (100.0)**	**53 (100.0)**
	p (all responses)[c]		*0.012*	*<0.001*
	p (operating vs. not operating)[c]		*0.004*	*<0.001*

[a] Not all GPs answered each question and some data from the practices was missing

[b] Of the 53 who are clinical assistants, 24 are in dermatology, 11 in surgery, and 18 in others (oncology, ophthalmology and ENT)

[c] p values from Fisher's exact test comparing association between conducting operations and GPs with/without visiting dermatologist; GPs who are/are not clinical assistants. The p-value for operating vs. not operating was calculated after combining categories "on most occasions" and "on some occasions".

Percentages may not add up to 100.0 due to rounding

References

1. Lowy A, Brazier J, Fall M, *et al.* Minor surgery by general practitioners under the 1990 contract: effects on hospital workload. *Br Med J* 1993;**307**:413-7.

1. Lowy A, Brazier J, Fall M, *et al.* Quality of minor surgery by general practitioners in 1990 and 1991. *Br J Gen Prac* 1994;**44**:364-365.

2. McWilliam LJ, Knox F, Wilkinson N, *et al.* Performance of skin biopsies by general practitioners. *Br Med J* 1991;**303**:1177-9.

3. Cox NH, Wagstaff R, Popple AW. Using clinicopathological analysis of general practitioner skin surgery to determine educational requirements and guidelines. *BMJ* 1992; **304**:93-6

5 Khorshid SM, Pinney E, Newton Bishop JA. Melanoma excised by general practitioners in NE Thames, UK. *Br J Dermatol* 1998;**138**:412-7.

REFERENCES 10

- Alexander F, Ricketts TJ, McKinney PA, Cartwright RA - Cancer registration of leukaemias and lymphomas: results of a comparison with a specialist registry. Community Medicine. 1989; 11(2): 81-9
- Beadle PC, Bullock D, Bedford G, Leach JF, Webb RA, Dent NA, Burton JL - Accuracy of skin cancer incidence data in the United Kingdom. Clin Exp Dermatol. 1982; 7(3): 255-260
- Benn RT, Leck I, Nwene UP - Estimation of completeness of cancer registration. Int J Epid 1982; 11: 362-7
- Berkel J - General practitioners and completeness of cancer registry. J Epidemiol Community Health 1990; 44(2): 121-4
- Black RJ, Simonato L, Storm HH, Demaret E - Automated data collection in cancer registration. IARC Technical reports No.32, 1998.
- Brenner H - Limitations of the death certificate only index as a measure of incompleteness of cancer registration. Br J Cancer 1995; 72(2): 506-10
- Coleman MP, Demaret E - Cancer registration in the European Union. Int J Cancer 1988; 42:339-45
- Craven NM, Roberts DL - Skin cancer registration in the UK. Br J Derm 1994; 131 (supp 44): 30-1
- Department of Health - The Health of the Nation: A Strategy for Health in England. Department of Health, HMSO:London, 1992.
- Holme SA, Malinovszky K, Roberts DL - Changing trends in non-melanoma skin cancer in South Wales, 1988-98, Br J Dermatol 2000; 143(6): 1224-9
- Jensen OM, Parkin DM, Maclennan R, Muir CS, Skeet RG - Cancer Registration: Principles and Methods, IARC Scientific Publications No. 95, 1991.
- Kardara M, Acquilla S, Forster D, McCarthy C, Stevenson J - Establishing baseline data in cancer registration in northern England: implication for Health of the Nation targets - J Epidemiol Community Health 1995; 49(2): 150-2
- Khorshid SM, Pinney E, Bishop JA - Melanoma excision by general practitioners in north-east Thames region, England. Br J Dermatol 1998; 138(3): 412-7
  Lucke TW, Hole DJ, Mackie RM An audit of the completeness of non-melanoma skin cancer registration in Greater Glasgow, Br J Derm 1997; 137(5): 761-3
- Maudsley G, Williams EMI - Variability of skin cancer registration practice in the United Kingdom, J of Epidemiol Community Health 1997; 51(3): 337-8
- Melia J, Frost T, Graham-Brown R, Hunter J, Marsden A, du Vivier A et al - Problems with registration of cutaneous malignant melanoma in England. Br J Cancer 1995; 72(1): 224-8
- Nwene U, Smith A - Assessing completeness of cancer registration in the North-Western region of England by a method of independent comparison. Br J Cancer 1982; 46(4):635-9

- Office for National Statistics - Cancer Statistics registrations, 1993. Series MB1 no.26, published 1999
- Osterlind A - Epidemiology on malignant melanoma in Europe. Acta Oncologica 1992; Vol. 31 No.5 (Reviews No.2): 903-8
- Parkin DM, Muir CS, Whelan SL, Gao YT, Ferlay J, Powell J - Cancer Incidence in Five Continents. IARC Scientific Publications Vol VI, No. 120, 1992.
- Richards C, Richards H, Pheby D - Skin cancer: how accurate are local data? Br Med J 1995; 310(6978): 503
- Roberts DL - Incidence of non-melanoma skin cancer in West Glamorgan, South Wales. Br J Derm 1990; 122(3): 399-403
- Robles S, Marrett LD, Clarke EA, Risch HA - An application of capture-recapture methods to the estimation of completeness of cancer registration. J Clin Epidemiol 1988; 41(5): 495-501
- Sabri K, Harvey I - The prevention of skin cancer:is there a gap between evidence and practice? Public Health 1996; 110(6):347-50
- Schouten LJ, Hoppener, van den Brandt P, Knottnerus JA, Jager JJ - Completeness of Cancer Registration in Limburg, the Netherlands. Int J Epidemiol 1993; 22(3): 369-76
- Seddon DJ, Williams EMI - Data quality in population-based cancer registration:an assessment of the Merseyside and Cheshire Cancer Registry. Br J Cancer 1997; 76(5): 667-674
- Swerdlow AJ, Douglas AJ, Vaughan Hudson G, Vaughan Hudson B - Completeness of cancer registration in England and Wales: an assessment based on 2,145 patients with Hodgkin's disease independently registered by the British National Lymphoma Investigation. Br J Cancer 1993; 67(2): 326-9
- Villard-Mackintosh L, Coleman MP, Vessey MP - The completeness of cancer registration in England: an assessment from the Oxford-FPA contraceptive study. Br J Cancer 1988; 58(4): 507-511
- Yorkshire Cancer Organisation (YCO) - Cancer in Yorkshire: Cancer Statistics 1989-93. YCO, Cancer registry report, 1996.

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CANCER OUTCOMES MONITORING

REGISTRATION OF SKIN CANCER IN YORKSHIRE

A Study into the Completeness & Validity of Cancer Registry Data