

## 3.1. DATA COLLECTION METHODS

### 1 SOURCES OF DATA

Reporting to the Registry is voluntary, and data collection is mainly active. The only information received passively at present is on notification forms returned by general practitioners. All other information is actively gathered by eighteen nurses trained in cancer registration methods who are employed by the Registry with the title of Tumour Registration Officer (TRO). These TROs are based in hospitals around the country. Each is responsible for gathering cancer data from a group of hospitals, and from other sources within a designated geographical area. Within their catchment areas, they liaise with hospital pathology and haematology laboratories, special clinics, hospital administrators and medical records staff, Hospital Inpatient Enquiry (HIPE) and casemix staff, and any other persons they consider to be a useful source of cancer registration data. They also maintain links with public health nurses, hospices and nursing homes in the community.

Most cases (20941; 98%) were first recorded in hospital. The predominant source of notification of cases (17550; 82% of the total) was through active registration by the tumour registration officers (TROs) from reports provided by pathology departments within hospitals (Table 3.1).

**Table 3.1. Source of notification of cases**

SOURCE	CASES	% OF ALL CASES
<b>tumour registration officer notifications</b>	<b>20941</b>	<b>97.6%</b>
<i>pathology</i>	17550	81.8%
<i>hospital inpatient enquiry (HIPE)</i>	1954	9.1%
<i>other inpatient</i>	863	4.0%
<i>other outpatient</i>	479	2.2%
<i>radiology</i>	95	0.4%
<b>death certificate</b>	<b>210</b>	<b>1.0%</b>
<b>GP</b>	<b>108</b>	<b>0.5%</b>
<b>other sources</b>	<b>167</b>	<b>0.8%</b>
<b>not recorded</b>	<b>24</b>	<b>0.1%</b>
<b>all cases</b>	<b>21450</b>	

The most important non-hospital source of cases (210; 1.0%) was death certificates. The Registry has access, through the Central Statistics Office, to all death certificates issued since January 1994, and keeps a copy of death certification details on every death. The Registry, at present, does not register a case based on death certification alone, but only after the diagnosis has been confirmed from another source. Our reason for doing this is that almost all cases which first come to our attention from death certificates have turned out to pertain to pre-1994 incident cases. On the basis that almost all current death certificate only (DCO) cases are likely to pre-date the establishment of the Registry, we have decided to exclude them for the present.

Cancer cases are also notified to the Registry by general practitioners. The number of new cases from this source is quite small (108; 0.5%), but notification by GPs is a valuable check on the completeness of registration from other sources, and is our only source of information on cancer cases treated solely by GPs.

Data acquisition from the HIPE system is done at hospital level, as we have no access to identifiable HIPE data centrally. This is in marked contrast to the situation in Northern Ireland, where the equivalent data is the main source of cancer registrations.

## 2 DATA RECORDING

Data is entered directly onto laptop computers by the TROs. The TRO enters or updates data under three headings: patient, tumour and treatment information (Table 3.2). Some of this information comes from the pathology report or other source of initial notification, but most is extracted from the patient's records when these become available to us, usually some weeks after discharge. The date, cause and place of death are entered by linkage with death certificates and the ward/DED data by linkage of the address with a national address database.

**Table 3.2. Data collected**

PATIENT	TUMOUR	TREATMENT
name - surname, first name, maiden name, other name	source of notification	treatment type
address: four fields	method of presentation	treatment date
other address(es)	GP	hospital
ward/district electoral division of residence*	hospital	consultant
GMS number	consultant	
RSI number	medical record number	
VHI number	incidence date	
date of birth	age at incidence	
sex	topography	
smoking status	morphology	
marital status	grade	
occupation	behaviour	
occupational status	method of diagnosis	
alive or dead*	TNM stage (clinical and pathological)	
date of death*	basis of staging	
cause of death*	residual disease	
place of death*	sites of metastases	
	histology date, lab, pathologist and reference number	

\* added by data linkage

### 3.2. QUALITY CONTROL

The Registry carries out internal quality control checks on the data throughout collection and processing. Details of these procedures have been given in earlier reports.