Appendix 3 (b) The Thames Cancer Registry

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Introduction

The Thames Cancer Registry, in terms of the population covered (over 13 million) is the largest cancer registry in western Europe. It evolved from the South Metropolitan Cancer Registry which began operation in 1958, became the South Thames Cancer Registry in 1974 and, by combining with the two North Thames Cancer Registries in 1985, reached its present form.

Information collected

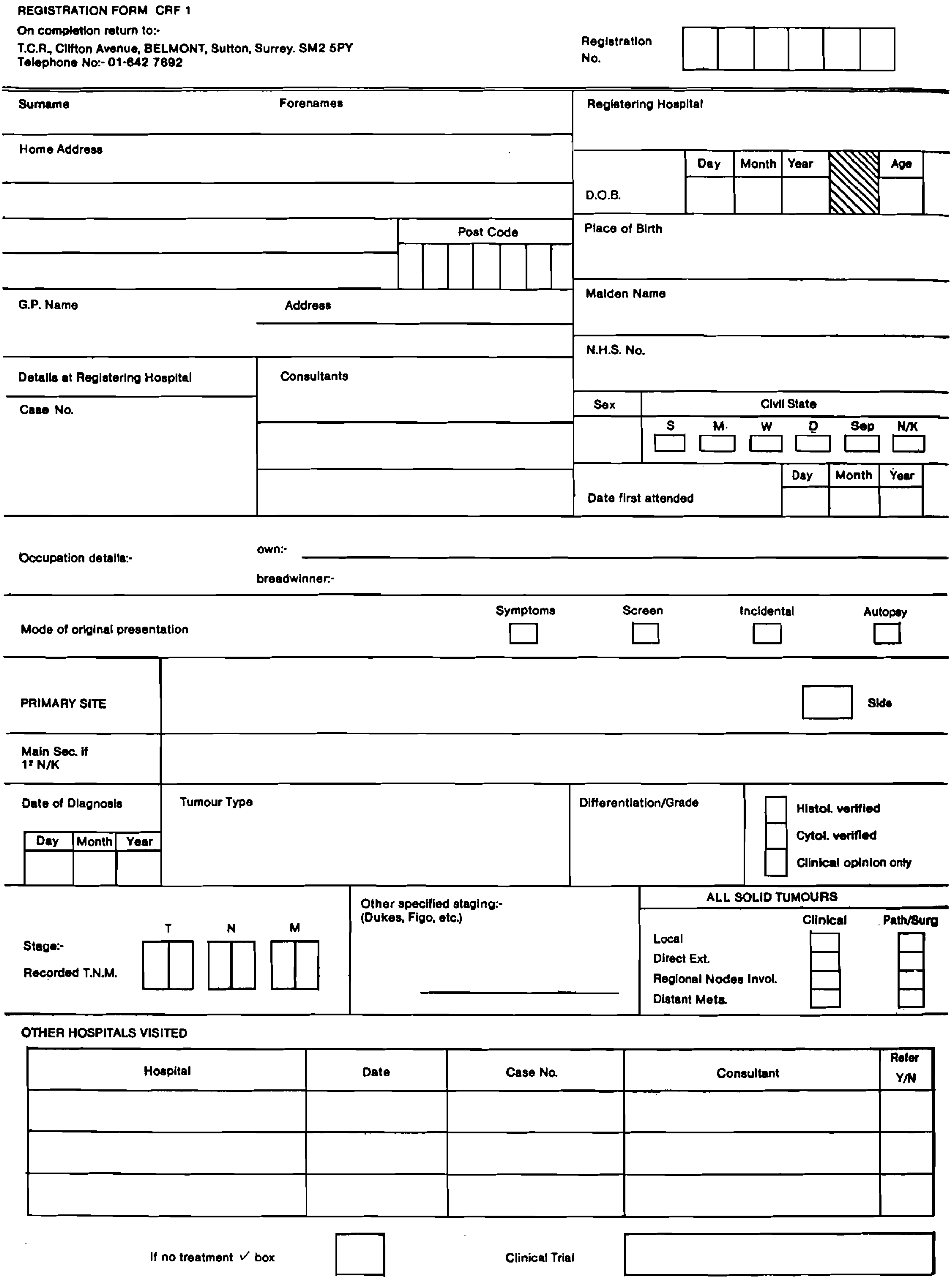
The Thames Cancer Registry aims to be a compromise between a basic minimal system and a highly detailed information system holding vast quantities of data in a complex data set. Data items have been selected on the basis of their being demonstrably useful, acceptably accurate and complete in the primary source documents (usually hospital records) and capable of being stored by computer in a retrievable and analysable form. The registration form, on which almost all cases are registered, is shown in Figures 1 and 2.

Identification details

The patient's name, forename, sex, date of birth and address are recorded to enable incoming registrations to be checked against the index of registered cases to avoid duplication. The post code is not always recorded and special procedures are used to deal with those which are missing (see below). The National Health Service number is of great value to the follow-up of live patients, as described below, but unfortunately is poorly recorded by hospitals. The maiden name and place of birth are useful to resolve cases of doubt in matching cancer registrations against the National Health Service Central Register when the National Health Service number is unknown.

Hospital details

Details are held for each hospital the patient has attended, unless referred only for an opinion while the main treatment is carried out elsewhere. The name of the hospital, date first attended, hospital number and consultants seen are recorded.



REGISTRATION FORM CRF 1

On completion return to:-
T.C.R., Clifton Avenue, BELMONT, Sutton, Surrey. SM2 5PY
Telephone No:- 01-642 7692

Registration No. ☐☐☐☐☐☐

Surname
Forenames
Registering Hospital

Home Address

Post Code ☐☐☐☐☐☐☐

	Day	Month	Year	▨	Age
D.O.B.				▨	

Place of Birth

G.P. Name
Address

Maiden Name

N.H.S. No.

Details at Registering Hospital

Case No.

Consultants

Sex	Civil State					
	S	M	W	D	Sep	N/K
	☐	☐	☐	☐	☐	☐

	Day	Month	Year
Date first attended			

Occupation details:-
own:-
breadwinner:-

Mode of original presentation
Symptoms ☐ Screen ☐ Incidental ☐ Autopsy ☐

PRIMARY SITE ☐ Side

Main Sec. if 1° N/K

Date of Diagnosis

Day	Month	Year

Tumour Type

Differentiation/Grade

☐ Histol. verified
☐ Cytol. verified
☐ Clinical opinion only

Stage:-
Recorded T.N.M.
T ☐☐ N ☐☐ M ☐☐

Other specified staging:-
(Dukes, Figo, etc.)

ALL SOLID TUMOURS

	Clinical	Path/Surg
Local	☐	☐
Direct Ext.	☐	☐
Regional Nodes Invol.	☐	☐
Distant Mets.	☐	☐

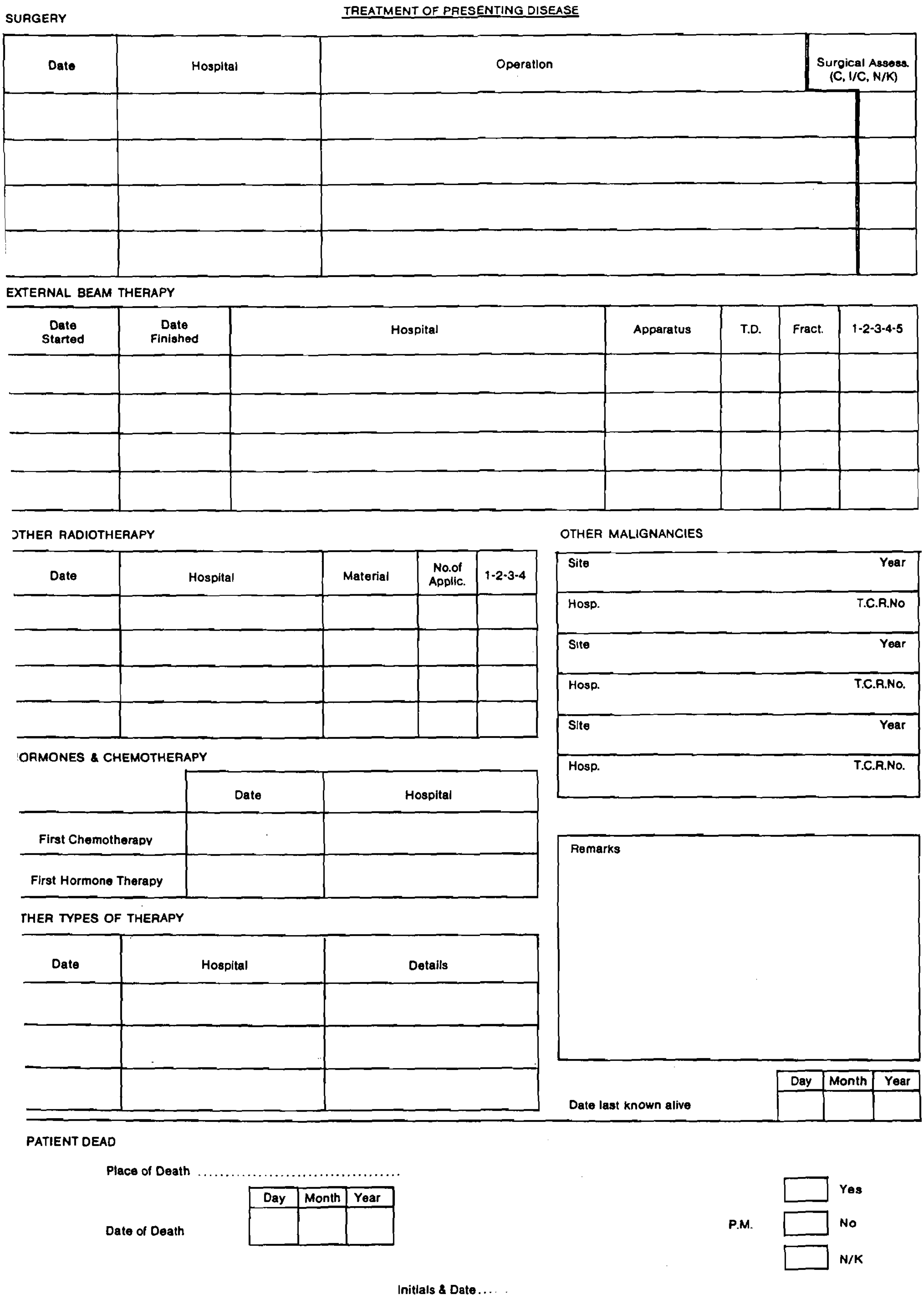
OTHER HOSPITALS VISITED

Hospital	Date	Case No.	Consultant	Refer Y/N

If no treatment ✓ box ☐

Clinical Trial

Figure 1. Thames Cancer Registry: registration form—front side



TREATMENT OF PRESENTING DISEASE

SURGERY

Date	Hospital	Operation	Surgical Assess. (C, I/C, N/K)

EXTERNAL BEAM THERAPY

Date Started	Date Finished	Hospital	Apparatus	T.D.	Fract.	1-2-3-4-5

THER RADIOTHERAPY

Date	Hospital	Material	No.of Applic.	1-2-3-4

ORMONES & CHEMOTHERAPY

	Date	Hospital
First Chemotherapy		
First Hormone Therapy		

THER TYPES OF THERAPY

Date	Hospital	Details

OTHER MALIGNANCIES

Site	Year
Hosp.	T.C.R.No
Site	Year
Hosp.	T.C.R.No.
Site	Year
Hosp.	T.C.R.No.

Remarks

	Day	Month	Year
Date last known alive			

PATIENT DEAD

Place of Death ....

	Day	Month	Year
Date of Death			

P.M. ☐ Yes ☐ No ☐ N/K

Initials & Date.....

Figure 2. Thames Cancer Registry: registration form—reverse side

Clinical details

As well as recording the site and histology of the tumour, every effort is made to record the clinical stage at presentation. Where details of the TNM or other international staging systems are present in the hospital records, these are noted. For solid tumours, the simplified staging system described under data item 23 in Chapter 6 is used. Even where clinical notes are less comprehensive, it is usually possible to extract these data. For cases having surgery, the data item is repeated in the light of definitive information.

Treatment details

The recording of treatment details by a population-based cancer registry is something of a contentious issue and, if carried out, is always a compromise. The Thames Cancer Registry only attempts to record treatment given in the initial treatment plan, which normally excludes any therapy started more than three months after diagnosis unless pre-planned. For surgery, the nature of the operation and some assessment of its completeness are recorded. For external beam therapy (the details of which are almost always well recorded in hospital notes) the apparatus used, tumour dose, number of fractions and site of irradiation are noted. For other radiotherapy, the isotope used, number of applications and site irradiated are recorded. It is extremely difficult to collect hormono- and chemotherapy data in any meaningful way without recording a great deal of detail, which then begins to defy analysis. Effectively, the Thames Cancer Registry records only the fact of these treatments. Because stability is important to any long-term information system and frequent changes to the source documents are best avoided unless essential, a section for other types of therapy is included so that any new therapies can be flagged in the future.

Other malignancies

Where it is clear from the hospital notes that a patient has developed more than one primary cancer, basic details of previous or synchronous tumours are given to assist the linkage of this information within the computer system.

Vital status

Basic details of the patient's status at the time the case is abstracted are recorded. These may be supplemented later by details from a death certificate.

Data collection methods

Nearly all of the cases registered are abstracted by field staff (known as research clerks) employed by the Registry on a peripatetic basis. Each has a base hospital but also visits a number of other hospitals in the vicinity, wherever possible working within a group of hospitals which regularly refer patients to each other. In London itself, most of these clerks are employed full-time, but outside the capital they are more likely to be part-time to avoid unnecessary travelling between distant hospitals. Because they are members of the Registry staff they are selected, trained and supervised by the Registry, which ensures that as high a degree of consistency and expertise as possible is maintained. Training is a continuing process and study days are held to promote this. The research clerks are organized into four regional teams each having its own supervisor. A small number of hospitals provide their own equivalent of a research clerk, who is also encouraged to join in the Registry's training programme. Very often these clerks have other clerical duties not directly connected with cancer registration, and are found in hospitals which have an interest in maintaining their own information systems for cancer patients.

Every month the research clerks send completed registration forms to the Registry and receive computer listings of cases needing registration which have come to light by means of, for example, a death certificate for an unregistered cancer patient. They also receive a list of queries requiring resolution, e.g., cases having a dubious diagnosis, missing details or contradictory information.

While a system of peripatetic field workers has a great deal to commend it, for a large registry it involves considerable expense and administration. On a day-to-day basis, the research clerks work unsupervised and in an environment where they are seen at best as visitors or at worst as intruders. Relationships with hospital staff have to be patiently cultivated—which may be difficult where the visitor is more permanent than the staff of the hospital itself. Firmness must be coupled with tact, since neither a weak nor overbearing research clerk will be successful. In selecting such staff for appointment, personality is as important as qualifications.

Other data sources

Death certificates

Like many other registries, the Thames Cancer Registry receives copies of death certificates for patients who die within its geographical area, and for whom malignant disease is mentioned as the underlying or contributory cause of death. The treatment of death certificates is outlined in Figure 3. Where the certificate relates to a previously registered patient, the computer record is amended accordingly. For unregistered patients dying in hospital, the research clerk at the hospital is notified and asked to make a registration. Where the patient dies at home, the Registry writes to the certifying doctor requesting details of any hospital the patient has attended. If the patient never attended hospital, the case is registered on the basis of the certificate itself.

Histology reports

With the rapid development of computerized pathology systems, the Thames Cancer Registry is working towards a system of preliminary notification of malignancies by transferring data between the pathology computers and the Registry's computer.

Computerization of data

All the information recorded on the registration form is transferred to the computer. The Thames Cancer Registry uses a sophisticated system in which the entire data-

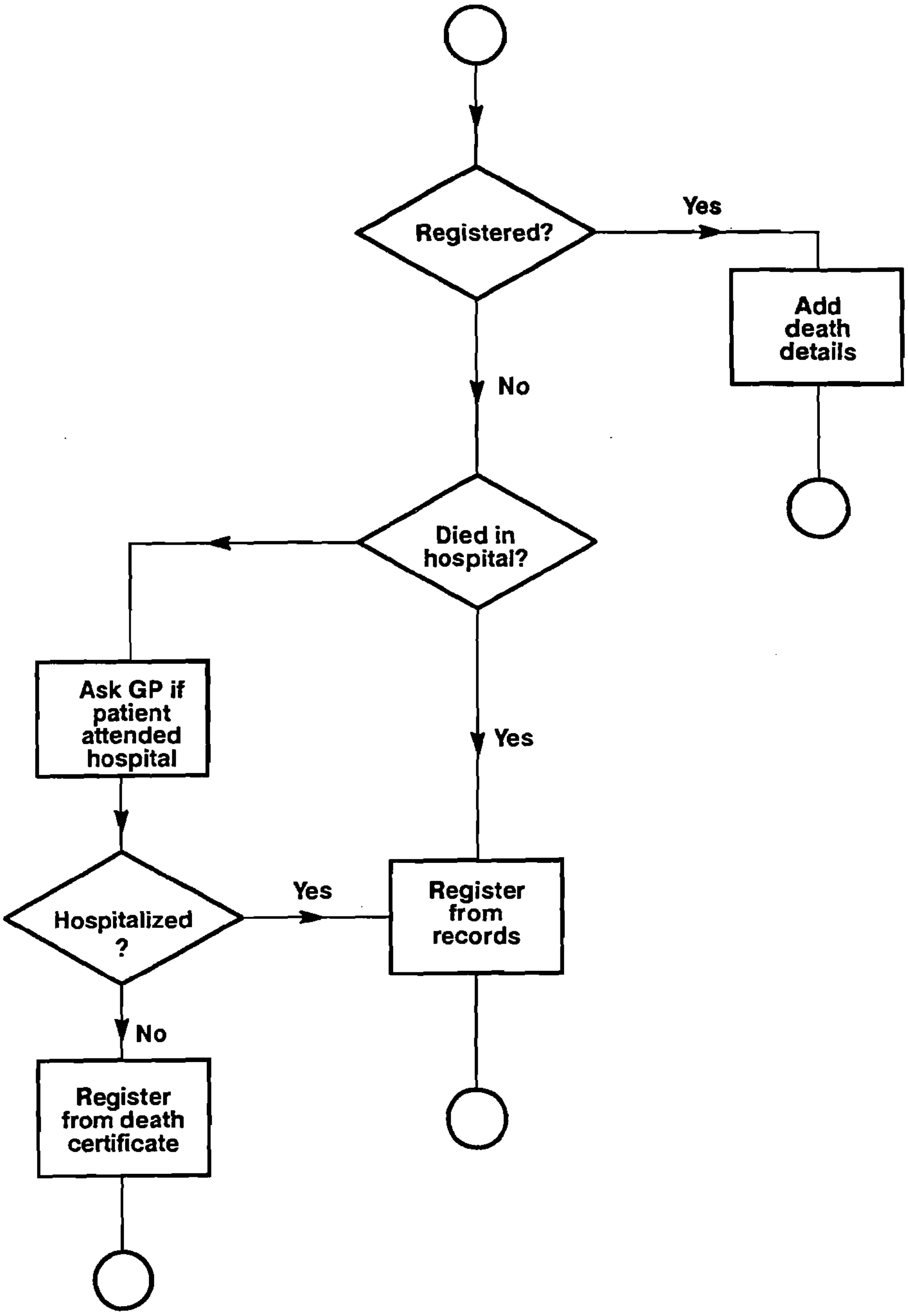


Figure 3. Thames Cancer Registry treatment of death certificates

base for the Registry is held online, that is, stored on disk, enabling details of any case to be recalled instantly on a visual display unit. The records are indexed so that any case can be retrieved by number, name or, using the analytical programs, by diagnosis.

Record linkage

The first task to be carried out on each incoming document is to check whether it relates to a person already registered. This is done by entering the name, sex and date of birth of the patient into the computer which then carries out a series of searches—

first for direct matches, then using a date of birth window—i.e., searching around the given date for a possible match, finally using a phonetic search in case the name has been spelled differently previously. If the operator is satisfied that this patient does not appear on the register, the computer automatically generates a patient number which will in future uniquely identify the patient. It assigns the same number to the tumour (the tumour number) which is now registered by entering the remaining data on the form. If the operator finds that the patient is already registered, details of the tumour (or tumours, if more than one primary is registered) are displayed on the screen. At this point the operator must decide whether the data on the form relate to a primary already registered or to another, unregistered, tumour. In the first case, the form is used to add further details to the existing information but, in the second, a new tumour number is assigned and the case registered in the ordinary way. Thus patients have only one patient number but may have more than one tumour number. The first tumour registered for each patient is the same as his or her patient number. In this way, individual primary tumours in one patient are counted separately but are linked by having the same patient number.

Coding of data

Data in the Thames Cancer Registry are held by the computer in coded form so that they are properly organized for analysis, but all data are entered in text form. The computer automatically translates the terms entered into code and translates the code back to text when the data are recalled. Sometimes the translated text is not exactly the same as the term originally entered. For example, the operator might enter 'Bile duct carcinoma' which the computer would code as 'M81603' but which would subsequently be recalled as 'Cholangiocarcinoma'. This system of 'preferred terms and synonyms' results in very flexible dictionaries which can be tailored to local terminology and abbreviations. It is possible for the user to interrogate the dictionary if difficult or ambiguous terms are encountered and new synonyms can be added as necessary. Among the data items coded in this way are Place of Birth, Hospital, Consultant, Occupation, Site, Histology, Operation, Radiotherapy Apparatus and Radio-isotope.

Consistency checks

Before leaving a case, the computer carries out a series of consistency checks and the operator is required to correct any errors detected.

Post coding and coding of areal details

From the post code of any address in Great Britain the local authority, electoral ward and health district of residence can be determined by reference to a computerized table, thus eliminating some of the most difficult manual coding undertaken by the Registry in previous years. Where the post code is not recorded on the registration form, the patient's address is submitted on magnetic tape to a bureau which specializes in the computerized post-coding of addresses. This is done on a quarterly basis, the post codes being fed back to the data-base, again using magnetic tape.

Retrospective checking for duplicates

It is almost inevitable that in a registry handling over 120 000 incoming documents per year, some duplication of registrations will occur. This may be caused by operator error, the use of different names by the same patient, or by other factors. Periodically, the computer generates a list of cases for a two-year period which have identical post codes and similar or identical site codes. Since one post code covers, on average, only 15 residential addresses, the chance of there being two cases of the same cancer within two years is quite slight and a close manual check is carried out to discover whether a duplication has occurred.

Generation of enquiries

The generation of further enquiries about a registered cancer case is very much a routine procedure and is readily computerized, which saves a great deal of clerical effort. For example, the generation of enquiries to hospitals or to general practitioners, as shown in Figure 3, is all carried out by the computer, the operator only having to key in the details on the death certificate. The system detects the need for further information and, after printing the initial enquiry, generates reminders at suitable intervals until the appropriate action has been taken.

Submission of data to the National Cancer Registry

A small sub-set of the data for each case resident in any of the four Thames Regions is passed to the National Cancer Registry maintained by the Office of Population Censuses and Surveys (OPCS). Data are submitted quarterly on magnetic tape to be merged with data from the other registries in England and Wales.

Follow-up

The Thames Cancer Registry uses a system of passive follow-up, in which all patients not known to have died or emigrated are assumed to be still alive. The deaths due to cancer are notified by death certificates (see Figure 3), but other arrangements are used to notify the Registry of the deaths of registered patients where this is due to causes other than cancer or where the death has occurred outside the Registry's geographical area.

These latter arrangements depend upon the Office of Population Censuses and Surveys, which, as well as maintaining the National Cancer Registry, also maintains the National Health Service Central Register, a manual index of the entire population of Great Britain. All registered cancer patients are flagged on the Registry so that when the patient dies, wherever this occurs and whatever the cause, the cancer registry concerned is notified.

Data analysis and information retrieval

The Thames Cancer Registry uses computer programs for the retrieval of data which are designed around the dictionaries and tables used to create the data in the first place. This functional relationship between output and input is important for maintaining an efficient and streamlined information service. Almost all *ad hoc* enquiries can be processed using user-friendly programs. Very little programming as such is required.

Organization of the registry

The Registry is organized into three functional units, data collection (the peripatetic research clerks), data-processing (VDU operators carrying out all the input operations) and information and research (scientific staff carrying out data output operations). It would be a mistake to view these units as independent of each other, and good communication between them is essential. This is carried out on an informal day-to-day basis, but a formal meeting of the heads of these units and the four data collection supervisors is held every month to review progress and discuss actual or potential problems. Effective lines of communication within the organization are a vital part of the maintenance of an effective and high-quality information system.