

Cancer Information in Scotland: A Summary of Data Flows and Uses

This information is intended to support clinicians and data protection officers who have been asked, by patients with cancer, for detailed information about the processing of their personal health records. It is not designed primarily to be a patient information leaflet, but rather to complement the generic patient information leaflet, 'Protecting Personal Information: A Guide for Patients', and the UK Association of Cancer Registries leaflet, 'About cancer registration', by informing the counselling of patients who ask for further details specifically about cancer information.

What are the main flows of information about patients with cancer in Scotland?

The Information Services (ISD Scotland) of NHS National Services Scotland registers information about all new cases of cancer arising in Scottish residents (the Scottish Cancer Registry or SMR06 record scheme) and collects information about hospital treatment of patients with cancer (the SMR01 scheme). Registration of cancer depends on several sources of information, to ensure that the data are as complete as possible. The General Register Office for Scotland registers information about deaths and, within a stringent framework of data confidentiality and security regulations, this information is shared with others to enable survival analysis. Several longstanding specialist tumour registries collect detailed information on all new cases of particular types of cancer in Scotland: these include the Scottish Melanoma Group, the Scottish Bone Tumour Register, and the National (UK) Register of Childhood Tumours. Information is also collected to enable the cancer screening programmes to run and to monitor their success. In addition, the regional networks of clinicians treating cancer collect information about their patients so that the quality of cancer services can be assured. To ensure the accuracy of all these data (a requirement of the fourth principle of the Data Protection Act), the various sources of data are sometimes checked against each other. But in practice, almost all analyses of cancer information are actually carried out on anonymised data.

What information is collected?

A wide range of information is collected, in keeping with the many uses described below. This will usually include the name, address, gender, date of birth, and CHI number of the patient, the type and location of the cancer, how advanced the cancer is, and the treatment received by the patient. Much of this information is extracted by trained NHS Clinical Coding staff from hospital medical records.

What is the information used for?

The information is used for a wide range of purposes, including:

- Public health surveillance, eg, monitoring trends in cancer incidence, investigation of possible clusters of cancer which have generated public concern
- Health service planning, eg, assessing future requirements for radiotherapy facilities, based on projections of cancer incidence

- Evaluating the impact of interventions, eg, tobacco control on incidence of smoking-related cancers, cervical screening on incidence of cervical cancer, treatment services on survival
- Supporting clinical audit and health services research, eg, recent audits of breast, prostate, colorectal, ovarian, and lung cancer, research demonstrating the advantage of specialisation and multidisciplinary care for certain cancers
- Supporting epidemiological research into the causes of cancer, eg, case-control and cohort studies
- Providing information to a wide range of organisations, eg, to support health promotion, cancer charities
- Supporting clinical geneticists in counselling their patients (see below)
- Supporting patient notification exercises (see below)

Why is it necessary to collect identifiable information?

There are five main reasons why, at present, it is necessary to collect information which identifies patients.

- Patients often attend more than one hospital. It is important to know that a cancer reported from a number of different hospitals relates, in fact, to the same person, otherwise cancer incidence rates would be misleadingly high.
- An important indicator of the effectiveness of cancer services is the percentage of patients who survive their cancer. It would not be possible to link a patient's date of death to their cancer records without identifying information.
- People are often concerned that there might be a high risk of cancer in their locality. These risks cannot be investigated properly without knowing where patients with cancer live (based on postcode of residence).
- People are often worried that their family history may put them at high risk of cancer. An accurate family history is crucial if these individuals are to be offered appropriate advice. The cancer registry is often asked by clinical geneticists to confirm the details of a cancer diagnosis in a relative of someone attending their clinic. In the case of living relatives, this information is only released with the written informed consent of the relative concerned. Often, especially when medical records have been destroyed, the cancer registry is the only available source of such information.
- Occasionally, a previously unforeseen, significant late effect of therapy comes to light many years or even decades after that treatment was in widespread use. In these circumstances, it will be necessary, using all available information sources including the cancer registry, to try and trace all patients who might be at risk, so that they can be informed and counselled about possible interventions to reduce their risk.

Confidentiality of information collected and processed by NHSScotland

All information collected and processed by NHSScotland is regarded as highly confidential, and data security is taken very seriously. It is a requirement, under the Data Protection Act, for collections of personal information to be notified to the Office of the Information Commissioner. Conditions for release of information from NHS Information

Services (ISD Scotland) which might identify an individual are very stringent, and information is only released in one of the following circumstances:

- when the individual concerned has given their written informed consent.
- when one of the consultants responsible for a patient requests information, usually for the purpose of follow-up.
- when approval has been obtained from the Caldicott Guardian of the hospital in which the patient was seen.
- when approval has been obtained from the Director of Public Health of the health board in which the patient resides.
- when approval has been granted by the national Privacy Advisory Committee, usually in conjunction with approval from the Multicentre Research Ethics Committee.

What are patients entitled to expect?

As well as the right to access their own personal information under the provisions of the Data Protection Act (1998), patients have the right to be informed about the processing and uses of their information, and the right to object to their information being used in certain circumstances, whenever practical. When a patient expresses a wish to “opt out” of cancer registration, it is important to explain what the cancer registry is, what information is collected, and what the information is used for (see above). Ideally, this explanation should be provided by someone who knows the patient well and has established a good relationship with them. It is important for patients to be fully informed of the potential consequences of their “opting out” before they make this choice. For example, the decision to “opt out” may have

- implications for them personally – for example, it may not be possible to identify them as being at risk in future patient notification exercises. In general, as hospitals become increasingly dependent on computerized records in the interests of efficiency, it may not be possible to guarantee that a decision to “opt out” will not affect care in any way.
- implications for their descendants – who may be deprived of complete information on their family history, leading to an inaccurate assessment of their risk, and inappropriate management.
- implications for society – since the more people who choose to “opt out” of having their information included, the less useful the information becomes (for example, in the context of investigating a possible cluster of cancer, or identifying a problem with cervical screening or cancer treatment services).

It is also important to bear in mind that the use of cancer registry data to support genetic counselling and patient notification exercises is a relatively recent development which was not anticipated 15 years ago. It is not possible to predict other future potential uses of the data which might also place at a disadvantage patients who choose to “opt out”. While it is important to discuss the potential disadvantages to the patient (and society) of “opting out”, patients should not feel pressurised into agreeing to registration.

How do patients “opt out”?

Cancer is not a statutorily notifiable disease in Scotland and registration is mainly not based on notifications from individual clinicians. Instead, the registry has to use multiple sources of ascertainment, including computerized hospital discharge records, pathology records and death records, among others. The registry often processes several records from such sources to create a single validated cancer registration. If, after counselling, a patient still wishes to “opt out” of inclusion on the cancer registry, *none* of their records should be transmitted to the cancer registry. This will require either the flagging or the deletion of *all* their cancer-related records on *all* computer (and manual) systems feeding the cancer registry. In practice, it may be difficult to achieve flagging because of the limitations of current hospital computer systems, and it may be difficult to delete records from hospital systems without compromising the management of the patient (and the running of the hospital). It may be wise to seek the advice of your local Data Protection Officer, Medical Records Manager, or Caldicott Guardian. It is important to bear in mind that patients with cancer are quite often treated in more than one hospital. Again, it may be necessary to seek the advice of the Data Protection Officer, Medical Records Manager, or Caldicott Guardian in other relevant hospitals. If it is not possible to *guarantee* that no records will be transmitted to the cancer registry, the only viable alternative is for the cancer registry to retain a record of the person’s identifying details without any clinical details attached so that any relevant records received by the cancer registry can be deleted. This arrangement and the reasons for it must be explained to the patient and, assuming they agree, their name and other identifying details should be supplied to the cancer registry (contact details at the end of this document). It should be noted that this arrangement will not prevent the transmission and retention of other identifiable cancer-related information, for example, through the SMR01 (hospital discharge) records scheme.

Some patients might be willing to have their details recorded on the cancer registry and used to contribute to local and national statistics about cancer and for other purposes including research that does not involve patient contact. They might wish only to opt out of the possibility of being included in any research projects involving direct contact with patients. If this is the case, the cancer registry will flag the patient’s cancer registration records to ensure that their details would never be released to researchers for any research project involving patient contact.

Where is it possible to obtain information about cancer in Scotland?

A wide range of anonymised information on cancer in Scotland is available on the Information Services (ISD Scotland) website at:

http://www.isdscotland.org/cancer_information

For further information about cancer registration, contact the Director of Cancer Registration in Scotland at:

Scottish Cancer Registry
Information Services (NHS National Services Scotland)
Gyle Square
1 South Gyle Crescent

Edinburgh
EH12 9EB

Telephone: 0131 275 6000