This leaflet explains what you need to know about cancer registration and why it is so important for the future care of cancer patients.

What is cancer registration?
When someone is diagnosed with cancer or a condition that might lead to cancer, healthcare staff record details about their diagnosis and the treatments they receive. Key parts of that information are passed to the Scottish Cancer Registry and Intelligence Service, which incorporates a national registry of cancer. This service is provided by Information Services Division (ISD), which is part of NHS Scotland. This leaflet explains that process and why this is done.

Why does ISD have a cancer registry?
By collecting information nationally, ISD can plan and improve health and care services that will support patients in the future by learning about:

- what types of cancers are most common
- how successful different treatments for cancers are
- the causes of cancer
- how cancer patients are treated across the UK

How is the data collected?
Information is brought together by ISD from different systems used for managing patient care across Scotland. These include information on screening services, outpatient appointments, hospital test results, admissions to hospital for treatment, details about treatments, waiting times and changes in health or quality of life resulting from the care.

What personal information will the registry hold about me?
The registry will hold some personal details including your:

- name
- address
- age
- gender.

as well as the information about your treatment.

We may also get information on other health conditions that you have as we want to understand if those conditions affect cancer.
Who uses the information in the registry?
ISD staff managing the registry collate and check the information. Information is then shared with a range of NHS staff, including cancer clinicians and other healthcare professionals and researchers. This is done only when appropriate, under secure conditions and with details that could identify you removed as far as possible.

Do I need to do anything?
No. There are no forms to fill in and nothing to sign. Secure automatic processes transfer the information from the hospital systems electronically to the registry.

Will anyone contact me from the registry?
No one from the registry will contact you. There are very rare occasions when cancer researchers need to access information about individual patients. They cannot contact you without the approval of your doctor.

Is information about me safe?
Yes. We have to comply with the law to use your personal information.

The reports that the registry publish do not identify any individuals. ISD staff are bound by data protection legislation and confidentiality rules. All information is stored in ways that comply with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 on computers that can only be accessed with secure passwords.

Only NHS staff with specific security access can see any personal details.

We sometimes release non-personal information to approved cancer researchers under strict conditions.

Your Rights
Data Protection law gives you rights over how we use your personal details. These and other more detailed information can be found in our Data Protection Notice (https://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/docs/SCRIS-data-protection-notice-190731.pdf).

Where can I get more information?
You can ask your doctor or nurse, another member of your healthcare team, or your hospital’s data protection officers.

Or write to:
Director of the Scottish Cancer Registry, NHS National Services Scotland, Information Services Division, Gyle Square, 1 South Gyle Crescent, Edinburgh EH12 9EB

Or email: nss.CancerReg@nhs.net

Or visit the national cancer registry website at isdscotland.org/SCRIS

If you would like this leaflet in a different language, large print or Braille (English Only), or would like the information on how it can be translated into your community language, please phone 0131 275 6665

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