Who are we?
We are Information Services Division (ISD) which is part of a Strategic Business Unit of NHS National Services Scotland (NHS NSS). NHS NSS is a public organisation created in Scotland under Section 10 of the National Health Service (Scotland) Act 1978.

ISD compile, manage and utilise the wealth of Scotland’s national health and care datasets, supporting decision-makers with information, intelligence and tools to assist in planning and managing local health and care services. ISD provides health information, health intelligence, statistical services and advice to support those tasks.

More information about ISD is available at https://www.isdscotland.org/About-ISD/ docs/HPS_ISD_Data_Protection_Notice_ V5-0_Final.docx

and more information about NHS NSS is available at https://nhsnss.org/how-nss-works/data-protection/

What is this notice about?
This is a Data Protection Notice about the Scottish Cancer Registry and Intelligence Service (SCRIS). It tells you about the way we collect, store and use personal information. It also tells you what your rights are under data protection law, how you can request to see your information and what to do if you have any concerns about our management of personal information.

About the Scottish Cancer Registry and Intelligence Service (SCRIS)
Whenever someone who lives in Scotland is diagnosed with cancer or a condition that sometimes leads to cancer, the doctor or hospital records the relevant details about their care and treatment. This applies to people of all ages, including children. Hospitals and doctors pass some of this information (for example, type of the cancer and stage of the cancer) to the Scottish Cancer Registry, which is maintained by ISD.

Cancer is a complicated disease and registration information allows us to understand it much better. It helps in the planning, research and improvement of health and care services to ensure that patients receive the best possible care and support in the future. By using cancer registration information we can:

- see how many people are getting cancer and what types of cancer they have across Scotland
- work with cancer researchers to identify the causes of some cancers
- look at how cancer patients are treated and how successful treatments have been for different types of cancer
- compare data on Scottish patients with other countries, subject to appropriate agreements being in place.
- ensure cancer screening programmes are working
- look at whether the number of people getting cancer is going up or down so we can make sure the right services and staff are available in the right place.

SCRIS is an initiative by ISD and the Innovative Healthcare Delivery Programme (IHDP https://www.ed.ac.uk/usher/ihdp) to further develop the existing Scottish Cancer Registry and expand its use in improving our understanding of cancer in Scotland, and to help make improvements to the care of cancer patients.

SCRIS brings information already received for Cancer Registration purposes together with other NHS data on cancer patients and make these available via a national database accessible by doctors, and other approved NHS staff and researchers. The information stored in this national database is used to support the review of cancer services and enables future improvements to the care of cancer patients.

Why do we need to collect and hold your personal health information for the Scottish Cancer Registry?

Personal information is information that identifies you. It includes things like your name, address, date of birth and postcode.

In order to register your case of cancer we need to know your name, address, age and gender, as well as information about the type of cancer or condition you have, and your treatments. As the data that feeds into the Scottish Cancer Registry comes from a wide range of sources we also need information that identifies you to make sure we can match all the data that relates to you across all of these sources.

Once the cancer registration process is complete we may wish to look at other factors, including other conditions, which could affect the longer term outcomes of all patients with a particular type of cancer. To do this we match details of patients on the Scottish Cancer Registry with other health datasets. Information on name, date of birth, gender and postcode from all these datasets will be used to combine, or link, the datasets for further analysis, such as survival analysis. The results of these analysis help to improve care for cancer patients in the future. Patient privacy is safeguarded when the Scottish Cancer Registry is linked with other health datasets by first carrying out a data protection impact assessment, ensuring that only a minimum number of NHS staff will have access to identifiable data, and ensuring that researchers only have access to identifiable data under strictly controlled and secure conditions.

Having this information means that the NHS and researchers can:

- assess how safe and effective a treatment is
- check that the NHS is providing a good service and spending public money properly
- plan how many beds, clinics and staff are needed
- monitor particular cancers or other related diseases (epidemiology)
- carry out public health or clinical research
- report on performance against national treatment standards and targets.
What is our legal basis for using personal health information?

We have to comply with the law to use your personal information, and that requires us to demonstrate we have a clear need to use this information. We use the personal information in order to carry out work we are legally obliged to do in the public interest. For example, planning delivery of cancer services, monitoring the quality of cancer services, and monitoring patterns of illness and the health needs in the population.

Because the personal information we use relates to health, it is considered to be ‘special category’ information under the law. Our legal basis for using this special information is usually that it is necessary for one of these reasons:

- For the provision of cancer care or treatment or the management of cancer care systems and services.
- For research aimed at improving cancer care and treatment.
- For statistical purposes (for example, cancer epidemiology).

Where do we get your personal information from and how do we use it?

Whenever someone is diagnosed with cancer, or a condition that sometimes leads to cancer, the doctor or hospital records the relevant details. This applies to people of all ages, including children.

Parts of this information, including personal health information are extracted from individual records and sent to the Scottish Cancer Registry. ISD work with staff in organisations such as NHS Boards, GPs, and hospitals to ensure this information is shared securely and legally.

ISD uses this, to register information about all new cases of cancer arising in Scottish residents and collects information about hospital treatment of patients with cancer.

ISD uses an electronic registration system to bring together all this information into the Scottish Cancer Registry which creates provisional registration records.

Data collection for the Scottish Cancer Registry is an automatic, centralised process which pulls information from a wide range of data systems in hospitals into a national repository called the SCRIS Cancer Intelligence Platform. Data sources include information from hospital discharges, hospital outpatient attendances, pathology records, chemotherapy records, radiotherapy records, prescribing records, cancer screening records, cancer waiting times, patient experience and mortality records.

We provide vital information and analysis for a wide range of NHS staff, including cancer clinicians and other healthcare professionals. This gives them better access to cancer related information, helping them to understand the disease better, what treatments have been most effective and assist in planning services, treatments and resources to help improve quality of cancer care. SCRIS also provides opportunities for cancer researchers to access information to generate benefits for future patients.

The information held by ISD in the Scottish Cancer Registry and the national database is not used for your current treatment. Instead it provides a retrospective view for more strategic and non-personal purposes of review, planning, research and improved cancer service in future.

An agreed selection of these data are analysed (for example; cancer incidence rates, cancer survival rates) and then presented to approved NHS staff in graphs and tables within an electronic system (the SCRIS dashboard).

It is essential that we protect patient data and ensure that confidentiality is maintained. Whenever possible the work ISD performs will be done using data which is not personally identifiable. Only
a limited number of NHS staff will have access to identifiable data, and only when this is necessary to ensure data or service quality, or to investigate specific incidents.

We also use this information to produce cancer statistics, analyse patterns and trends of cancer across Scotland, present this back to doctors and provide an analytical service for the NHS and researchers. The information can help us to identify possible causes of cancer and to find out about the best treatments.

We do most of our analysis with information that does not directly identify you, i.e. it does not hold your name, address and other immediately identifying information, in order to protect individuals’ privacy and to offer assurance to patients.

There are times when we have to use information that could identify you. Here are some examples.

- Reviewing samples of health records to make sure the information held is accurate.
- Linking information together from different data sets so that the outcomes of a particular cancer can be analysed.
- Providing information to an NHS Board about their patients or residents who have had treatment in other locations.

When another organisation requests information, it will only be released after removing as much information that could identify you as possible. We only release information that could identify you directly when required or permitted by law or when it can be shown that you gave your permission, for example, where you have signed a consent form to allow its use for clinical trials.

We take advice on sharing information from the Public Benefit and Privacy Panel for Health and Social Care (http://www.informationgovernance.scot.nhs.uk/pbpphsc/) which includes public representatives. This group helps to make sure we protect personal information and balancing the public benefit against any risk of harm to the individual.

**How long can we keep your personal information?**

We often retain health information indefinitely in accordance with our purposes of public interest in the area of public health such as epidemiology (monitoring trends in patterns of disease).

We are required to keep personal information as set out in the Scottish Government Records Management: NHS Code of Practice (Scotland) Version 2.1 January 2012 (https://www2.gov.scot/Publications/2012/01/10143104/9). The NHS Code of Practice sets out minimum retention periods for information, including personal information, held in different types of records including personal health records and administrative records. As directed by the Scottish Government in the Records Management Code of Practice, we maintain a retention schedule detailing the minimum retention period for the information and procedures for the safe disposal of personal information. This schedule can be found at https://nhsnss.org/how-nss-works/document-storage-and-retention/.

**How do we keep your personal information secure?**

We take care to ensure your personal information is stored securely and is only accessible to authorised people. Our staff have a legal and contractual duty to keep personal health information secure, and confidential. The following security measures are in place to protect personal information:

- All staff undertake compulsory training in Data Protection and IT security.
- NSS has to comply with the NHS Scotland Information Security Policy set out by Scottish Government.
We have senior staff who have the role of ‘Caldicott Guardian’ for our organisation. The job of a Caldicott Guardian is to ensure that we take all appropriate steps to protect the confidentiality of personal health information. As well as the Caldicott Guardian, we have a team of specialist staff to advise and ensure that information is handled properly and in accordance with the law.

Access to personal health information can only be given with special authorisation, and use of that information is closely monitored.

We have policy and procedures on the safe handling of personal information, from when we receive it to when it is securely removed or destroyed when no longer needed.

There are strict rules that govern how information should be managed e.g. to make sure names, addresses and any other information that might identify an individual are removed wherever possible before analysis.

When we publish reports from the information we hold, we ensure no-one can be identified from the information we publish.

When we work with personal information we make sure we only use the minimum information required for us to undertake our role.

Will anyone contact me?
No one from SCRIS will contact you. We sometimes release information under strict conditions to approved cancer researchers, or for ‘patient notification’ or ‘tracing’ exercises. For most cancer research, patients do not need to be contacted, but in some cases they do. If researchers need to contact you, they will only ever do this with the approval of your own doctor. An example of a patient notification or tracing exercise involved the release of information to the doctors of women treated for Hodgkin’s disease using radiotherapy who then contacted those who were identified as having an increased risk of breast cancer.

Your rights
This section contains a description of your data protection rights.

The right to be informed
As an organisation, we must explain how we use your personal information. We use a number of ways to communicate how personal information is used, including:

- this Data Protection Notice
- discussions with staff providing your care.

The right of access
You have the right to access your own personal information.

This right includes making you aware of what information we hold along with the opportunity to satisfy you that we’re using your information fairly and legally.

If you’d like to access your personal information, get in touch with us with the details of your request using the following contact details:

Do I need to do anything?
You do not need to do anything – there are no forms to fill in and nothing to sign. Your hospital or doctor will record all of the information relevant to your care on local data systems. Secure automatic processes will then transfer only the parts of these data that are relevant to SCRIS.
Once we’ve received your request and you’ve provided enough information for us to locate your personal information, we’ll respond to your request within one month (30 days). However we may take longer to respond – by up to two months – if your request is complex. If this is the case we’ll tell you and explain the reason for the delay.

The right to rectify personal information

If the personal information we hold about you is inaccurate or incomplete you have the right to have this corrected – this is called the right to rectification.

If it’s agreed that your personal information is inaccurate or incomplete we’ll aim to amend your records within one month, or within two months where the request is complex. If more time is needed to fulfil your request, we’ll contact you as quickly as possible to let you know. We can restrict access to your records to ensure that the inaccurate or incomplete information is not used until amended – unless there is a risk to patient safety. Your personal information comes to ISD from the health boards and hospitals involved in your care. In some cases your request may need to be referred to the relevant board or hospital for rectification.

If for any reason we’ve shared your information with anyone else, perhaps during a referral to another service for example, we’ll explain to them the changes needed so they can ensure their records are accurate.

If, when we consider your request fully, we don’t consider the personal information to be inaccurate then we’ll add a comment to your record stating your concerns about the information. If this is the case we’ll contact you within one month to explain our reasons.

If you’re unhappy about how we respond to your request for rectification, we will provide you with information on how you can complain to the Information Commissioner’s Office, or how to take legal action.

The right to object

You have the right to object to your personal health information being included in the Scottish Cancer Registry and this will not affect the immediate care you receive. However, if we don’t hold your information it may not be possible for your doctor to contact you in the future should it be identified that you are at risk, such as when an increased risk of breast cancer is identified in women treated for Hodgkin’s disease using radiotherapy. These are often called ‘patient notification exercises’ or ‘tracing exercises’.

Also, less information might be available to support a relative to help them understand their family’s history of cancer and their risk of developing the disease. This information is offered through genetic counselling services where people are concerned that their family history may put them at high risk.

If you would like to object to, or request restriction of, our use of your personal information, you can do this by getting in touch with the NHS NSS Data Protection Officer at the address given above. However in some cases we can override objections where there is a compelling reason for us to continue our processing.

The right to complain

We employ a Data Protection Officer to check that we handle personal information in a way that meets data protection law. If you’re unhappy with the way we use your personal information, please contact our Data Protection Officer:
For more information
The people responsible for advising on the use of personal information are the Public Health and Intelligence (PHI) Caldicott Guardian and the PHI Information Governance team at

NHS NSS
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB

Email: NSS.PHIinfogovernance@nhs.net
Switchboard: 0131 275 6000

For more details on SCRIS please visit our web pages at:
http://isdscotland.org/SCRIS

Or you can contact SCRIS direct by writing to:

Director of the Scottish Cancer Registry
NSS Information Services Division
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB

Tel: 0131 275 6000

Further general information on ISD is available at: www.isdscotland.org

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