About Cancer Registration Leaflet - updated August 2023

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?

If you are diagnosed with cancer or a condition that might lead to cancer, healthcare staff record details about your diagnosis and the treatments you receive. Key parts of that information are passed to the Scottish Cancer Registry. This service is provided by Public Health Scotland (PHS), which is part of NHS Scotland. This leaflet explains that process and why this is done.

Why does PHS have a cancer registry?

By collecting information nationally, PHS 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 cancer screening programmes are working
• the best locations to place staff and services for cancer service improvement

It is essential for the cancer registry to have a complete and accurate record of all new cancers that occur in Scotland. Without complete records, it would not be clear if variations in cancer occurrence or outcomes were real or due to missing information. Without accurate records, it would not be clear if variations in cancer occurrence or outcomes were real or due to differences in how cancers are classified and coded.

How are the data collected?

Information is brought together by PHS from different systems used for managing patient care across Scotland and the rest of the UK. 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

We also need to know about cancer related investigations, as well as information about your:

• type of cancer

• stage of cancer
• treatment

We may also get information on other health conditions that you have as we want to understand if those conditions affect cancer.

We use this information to produce cancer statistics, reports and for research. It can help us to identify potential causes of cancer and to find out about the best treatments, for example.

Who uses the information in the registry?

PHS 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, to fully comply with laws about the use of personal data, under secure conditions, and with details that could identify you removed as far as possible.

The Scottish Cancer Registry contributes to:

• Supporting the work of cancer genetic counselling services for individuals and families who may be at a higher risk of developing cancer.

• Providing appropriate information on cancer for ad hoc queries and bespoke data requests including audits and surveys.

• National and international policies, publications and studies that compare the occurrence and outcomes of cancer within Scotland and with those in other places.

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 directly.

Cancer registry information is used to help others accurately identify patients with cancer. This is usually to assess the quality of other cancer information but occasionally it may be for the purposes of contacting patients who have had cancer. To do this, anyone who wanted to contact you (such as researchers) would need to have complied with all regulations and laws about contacting patients.

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. PHS staff are bound by data protection legislation and confidentiality rules. All information is stored in ways that comply with the UK 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 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 given us permission to allow its use for clinical trials; or where disclosure is necessary to safeguard an individual, or others, or is in the public interest.

Depending on the situation, we may need to share personal information with others. If we do, we will only share appropriate, relevant, and proportionate personal information and we will comply with the law. Full details on how PHS uses personal data are available in our Privacy Notice (see below).
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 Privacy Notice (https://www.publichealthscotland.scot/our-privacy-notice/your-rights/)

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,

Public Health Scotland,

Gyle Square,

1 South Gyle Crescent,

Edinburgh

EH12 9EB

Or email: phs.cancerreg@phs.scot

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

Version: August 2023