



Patient Information Leaflet

Scottish Renal Registry

This leaflet explains what you need to know about the Scottish Renal Registry (SRR) and why it is important for the future care of patients receiving renal replacement therapy (RRT).

Who are we?

The Scottish Renal Register is part of the Scottish National Audit Program within Public Health Scotland (PHS). PHS is a national special health board of NHS Scotland, jointly sponsored by the Scottish Government and the Convention of Scottish Local Authorities (COSLA), which launched on 1 April 2020. More information about PHS is available at:

<https://www.publichealthscotland.scot/our-privacy-notice/organisational-background/>

About the Scottish Renal Register

Each hospital in Scotland collects information about the care of patients who have received RRT and compare it with nationally agreed standards.

What is the aim of the audit?

To record details about the patients receiving RRT and use this information to change clinical practice to improve the care these patients receive.

What are the benefits?

The SRR audit uses this information to learn more about your condition.

Including your information in this national audit helps us to plan future care and improve health and care services that will support patients who are receiving RRT in the future by learning about:

- quality improvement including audit & peer review
- research including basic demography & epidemiology
- service planning
- teaching

How are the data collected?

The data are collected from your hospital records and added to an electronic database used to gather all of the information about you and your care in the SRR.

What personal information will the audit hold about you?

Only relevant information about your treatment and care is collected. We do collect the following personal information about you:

- Name
- Postcode
- Date of Birth
- Sex
- Community Health Index (CHI) Number
- Your NHS Board

as well as the information about your care.

How do we use your data?

The data we collect in the SRR database is held electronically and securely within Public Health Scotland.

The SRR team managing the audit collate and check the information. Personal information is shared with clinical teams and hospital management who are directly involved in your care.

This information may be used for local or national projects and as part of research, but individual personal information will never be published. The Audit Steering Group controls who has access to the data. Sharing of the data is done only when appropriate, under secure conditions and with details that could identify you, removed as far as is possible.

Will anyone contact me from the audit?

You may also be invited to take part in other associated projects, related to SRR in the future, but you will be informed about them and be able to decide whether you want to participate or not. If you decide not to take part this will not affect the standard of care you receive.

As the SRR audit aims to assist clinical teams with improvements for all patients it is sometimes necessary to contact patients or parents when they are at home.

If there is a need to contact you, it would be by telephone or post and permission to contact you will be sought before you leave hospital.

There are occasions when researchers need to access information about individual patients. There are strict processes they have to go through to do this and they cannot contact you without the approval of your doctor.

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 will record all of the information relevant to your care on their information systems/records. Relevant information will be manually entered to the SRR database by appropriately trained auditors. Secure automatic processes will then transfer only the parts of these data that are relevant to the SRR database.

Is information about me safe?

Yes. We have to comply with the law to use your personal information.

The reports that the audit publish do not identify any individuals. Public Health Scotland 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.

Your rights

Data Protection law gives you rights over how we use your personal details. These and other more detailed information can be found on the PHS website

<https://www.publichealthscotland.scot/our-privacy-notice/>

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:

Scottish Renal Registry,

143c,

Gyle Square

1 South Gyle Crescent

Edinburgh EH12 9EB

Email: phs.srr@phs.scot

Website: <https://www.srr.scot.nhs.uk/index.htm>

Useful links to other organisations

Public Health Scotland

www.publichealthscotland.scot

Healthcare Improvement Scotland

www.healthcareimprovementscotland.org

Accessibility and translations

If you need this information in another format or a community language please contact:

Email: PHS.EqualityDiversity@nhs.net

Tel: 0131 275 7457

Text relay: 01800 275 7457

Website: <http://contactscotland-bsl.org/reg/>