Scottish Clinical Trials Research Unit (SCTRU)
Data Protection Notice

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Scottish Clinical Trials Research Unit (SCTRU) Data Protection Notice

Who are we?

The SCTRU is a clinical trials unit within the Information Services Division (ISD), which is part of a strategic business unit in NHS National Services Scotland (NHS NSS). NHS NSS, the common name for the Common Services Agency, is a public organisation created in Scotland under Section 10 of the National Health Service (Scotland) Act 1978.

NHS NSS has a statutory responsibility to provide or arrange for the provision of a range of healthcare, health improvement and health protection services to promote the improvement of the physical and mental health of the people of Scotland and assist in operating a comprehensive and integrated national health service in Scotland.


This Data Protection Notice has been produced by the SCTRU and only relates to the work that they do.

What do we do?

The SCTRU works closely with NHS partners and Universities, providing co-ordination and management for all aspects of clinical trials on behalf of the trial sponsor(s). The SCTRU has developed a reputation as a competent and professional trials unit with expertise in oncology trials including large multi-centre, national and international trials.

What is this leaflet about?

This is the SCTRU’s Data Protection Notice. 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.

What is Personal Information and Personal Health Information?

Personal information is information that identifies you. It includes things like your name, address, date of birth, NHS number or Community Health Index (CHI) number and postcode. If the information contains details of any health care you may have received it may be referred to as ‘special categories of personal data’. This can include information such as any care and treatment you have received and results of tests you have had as well as health and lifestyle information.

Why do we need to collect and hold your personal health information?

As a NHS organisation we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.
What is our legal basis for using personal health information?

The type and purpose of personal data collected in clinical trials is described in the patient information sheet and informed consent.

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 of people using health and social care services in order to undertake work that is in the public interest, for example health and care research. As well as complying with current data protection legislation, we also follow the UK Policy Framework for Health and Social Care Research.

As 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:

- to promote, support and facilitate recruitment in clinical trials
- to offer a complete service for the management and design of clinical trials both nationally and internationally.

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 members of staff with 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.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purposes of health and care research, or, where you have consented, to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

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

The personal data collected in the course of a clinical trial can be retained and processed for a period of 15 years or longer, or as described in the patient information sheet and consent form.

**What are your rights?**

You have a right to access information we hold that identifies you. You also have the right to withdraw from any studies you are involved with however we will keep the information about you that we have already obtained. Your rights to change or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

If you wish to object about how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Our Data Protection Officer can be contacted as follows:

NSS Data Protection Officer
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB
Tel: 0131 275 6000
Email: nss.dataprotection@nhs.net

Translation
If you require this information in another format or a community language please contact

Email: NSS.EqualityDiversity@nhs.net
Tel: 0131 275 7457
Textrelay 01800 275 7457
https://contactscotland-bsl.org/reg/

For more information

The people responsible for overseeing our use of personal information in the Information Services Division are the PHI Caldicott Guardian and the PHI Information Governance team at NHS National Services Scotland, Gyle Square 1 South Gyle Crescent, Edinburgh, EH12 9EB
Email: NSS.PHIinfogovernance@nhs.net
Switchboard: 0131 275 6000

Further general information is available at:
- www.isdscotland.org