



Data Privacy Notice for Patients and Service Users of the National Coagulation Centre.

How we protect and manage your personal data

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1. Purpose

The National Coagulation Centre (NCC) must comply with all applicable data protection, privacy and security laws and regulations in the locations in which we operate. We respect your rights to privacy and to the protection of your personal information. The purpose of this privacy notice is to explain how we collect and use personal information for the provision of your healthcare service in the NCC. The St. James's Hospital overall Privacy Notice is available for you to view at www.stjames.ie or on request from the Data Protection Office Dataprotection@stjames.ie in St James's Hospital

2. The information we process

To allow us to provide services to you, we collect and process various categories of personal information.

Personal information we collect may include:

- date of birth, address, next of kin,
- contact details, for example, mobile phone number, email address.
- notes and reports about your health needs
- results of investigations, such as laboratory tests and x-rays
- relevant information from other health and social care professionals,

We may also process certain special categories of information, which may include racial or ethnic origin, religious or philosophical beliefs, genetic data, and biometric data, for the purpose of uniquely identifying a person or data concerning a person's sex life or sexual orientation. When we collect any personal and/or special category information about you it will be for a clearly defined purpose.

3. Legal basis for processing

The NCC's lawful basis for processing personal data of service users is found in Article 6 (1) of the General Data Protection Regulation (GDPR) as follows:

1. Subsection (c): processing is necessary for compliance with a legal obligation to which the Hospital is subject.
2. Subsection (d): The processing is necessary in order to protect the vital interests of the person (referred to as the data subject in data protection language). This would apply in emergency situations such as in the Emergency Department when an individual is unconscious or sharing information with other emergency services.
3. Subsection (e): The processing is necessary for a task carried out in the public interest or in the exercise of official authority vested in the controller; for the Hospital this official authority is vested through the Health Act 2004 (as amended).

Under Article 9 of the GDPR, we process special categories of personal data where it is necessary:

1. processing is necessary to protect the vital interests of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent;
2. processing is necessary for the establishment, exercise or defence of legal claims or whenever courts are acting in their judicial capacity;

3. processing is necessary for reasons of substantial public interest, on the basis of Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject;
4. processing is necessary for the purposes of:
 - preventative or occupational medicine
 - for the assessment of the working capacity of an employee
 - for medical diagnosis
 - for the provision of healthcare, treatment or social care
 - for the management of health or social care systems and services, or pursuant to a contract with a health professional
 - in the interest of public health

In these instances, processing is lawful where it is undertaken by or under the responsibility of

- a health practitioner, or
 - a person who in the circumstances owes a duty of confidentiality to the person that is equivalent to that which would exist if that person were a health practitioner. For example, the outpatient clinic secretary, emergency department secretary, primary care centre staff
5. processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy;
 6. processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

4. How we obtain information

We may obtain your information from a variety of sources, including the information you give to us. We may also receive your personal information from third parties, for example, your GP, your dentist, your social worker, or pharmacist.

5. Your rights

You have certain legal rights concerning your information and the manner in which we process it. This includes:

- a right to get access to your personal information;
- a right to request us to correct inaccurate information, or update incomplete information;

- a right to request that we restrict the processing of your information in certain circumstances;
- a right to request the deletion of personal information (excluding medical records);
- a right to receive the personal information you provided to us in a portable format where possible;
- a right to object to us processing your personal information in certain circumstances;
- a right to lodge a complaint with the data protection commissioner.

6. Access to your health records

You can access your health records by making a subject access request (SAR). It is sufficient to write to the hospital, or the NCC. It is important that you provide satisfactory evidence of identification and a sufficient description of the data that you are looking for. We will deal with your request according to the Data Protection Access Request policy SJH:IM:002.

7. What is a data controller and who is the data controller?

Data controllers determine the purposes for which and the manner in which any personal information is, or will be, processed. A data controller can be the sole data controller or a joint data controller with another person or organisation. St James's Hospital is a joint data controller for the National Haemophilia Electronic Health Care record, with the other three hospitals with Haemophilia treatment centres in Ireland and is the sole data controller for health care records held solely with St James's Hospital.

8. Your information may be used to

- Review the care we provide for you to ensure it is of the highest standard
- Investigate complaints, legal claims or adverse incidents
- Protect wider public health interests
- Provide information for planning so we can meet future needs for health and social care services
- Provide information to prepare statistics on Health Service performance
- Carry out health audit
- Provide training and development
- Remind persons of appointments by text
- Communicate certain blood results by text (within defined programmes in the NCC)

9. What other use is made of your Information?

9.1 Research

Research has a vital role to play in the development of healthcare and health service delivery. St James's Hospital is an academic teaching hospital associated with Trinity College Dublin and we support and promote research activity within the hospital.

The NCC team may review your personal data to determine if you could be eligible for inclusion in any of the open clinical trials or research projects in the NCC, all of which will be subject to Research &

Innovation (R&I) and ethical approval and will need your explicit consent if you later decide to participate in the study.

9.2 Retrospective Chart Reviews

In accordance with the Health Research Regulations (2018, amended 2021), the NCC team may review your personal data for retrospective chart reviews, in order to investigate clinically important questions.

Retrospective chart reviews have to be approved by the St James's Hospital R&I Office and by the Research Ethics committee.

If approval is given by these bodies, your explicit individual consent is not required.

The data obtained from such retrospective chart reviews may be published in peer reviewed medical journals.

9.3 Statistical/Aggregated/Anonymised Data

Both the Hospital and the NCC provide statistical information to other organisations such as the Department of Health, Universities and other research institutions. The Hospital will make sure that you cannot be identified by anonymising the information. If it is not possible to anonymise the information, you will be contacted for your consent.

10. Sharing with third parties

You may also be receiving health or social care from providers outside of the NCC/ healthcare provider. In order to assist in this process:

1. we may make referrals on your behalf requiring the need to share your personal information with those providers in private or voluntary hospitals, specialists. We will only do so if there is a genuine need in order to ensure the highest quality of care is provided to you. We are careful only to share the information that is necessary for this purpose. Anyone who receives this information is also bound by confidentiality and the data protection laws.
2. Support from the electronic healthcare systems used to provide healthcare is provided by third party companies. The current list of those companies with whom personal data is shared with are Temperature Controlled Products (TCP), Valentia Technology, Crimsontide, DAWN. We will share your information under a formal agreement on the basis that anyone who receives your information protects it in the same way we would and in accordance with applicable laws.
3. In certain situations, we may have to disclose your personal information to other agencies, in accordance with legal requirements, i.e. Dept. of Social welfare, Department of Health, TUSLA, the Courts etc., or in an emergency situation to prevent injury to other persons.

11. Transferring information overseas

We may transfer your information to organisations in other countries when it is necessary to provide you with health and social care services. This is done so under a formal agreement to ensure the level of protection of your personal details is equivalent to that under GDPR.

For some individuals attending the NCC, we need to calculate their personal pharmacokinetics (what the body does to a drug) after clotting factor infusions, to decide on the best clotting factor treatment amount and schedule for that individual.

In these cases, we send information to an external institution (sometimes located outside of the EU) to conduct the complex calculations which are required and which cannot be done locally.

The information sent is the date, time and amount of clotting factor infused and the results of clotting factor laboratory tests.

The information is transferred with minimal personal identifiers (year and month of birth) and a unique identifier determined by the NCC – the code for matching this unique identifier to the Pharmacokinetic results is kept securely within NCC electronic storage.

The Pharmacokinetic results will be filed in the individual's electronic health record held in the NCC.

12. How do we keep your records secure and confidential?

We are committed to ensuring that your information is secure with us and with the third parties who act on our behalf. We have a number of security precautions in place to prevent the loss, misuse or alteration of your information.

All staff working in the NCC have a legal duty to keep information about you confidential and all staff are trained in information security and confidentiality. St James's Hospital has strict information security policies and procedures in place to ensure that information about you is safe, whether it is held in paper or electronic format.

Healthcare providers from the three Comprehensive Care Centres in Ireland (St James's Hospital, Children's Health Ireland at Crumlin and Cork University Hospital) and the haemophilia treatment centre at Galway University Hospital have access to a shared National Haemophilia Electronic Health Record for the purpose of delivering high quality healthcare to people and families with bleeding disorders.

The four hospitals are Joint Data Controllers for the National Haemophilia System, as outlined in the Joint Data Controllers Agreement, 2019.

13. Sharing Information – within the HSE

Within the HSE, the clinical information collected by a doctor or other healthcare professional or staff member authorized to process your data is not passed on to others within the HSE, unless it is considered necessary for your health or social care needs or for one of the other reasons set out above (where possible, the personal information is anonymised or pseudonymised).

14. Retention period

We will only retain information for as long as necessary. Records are maintained in line with the recommendations of the HSE retention policy, which can be found at <https://www.hse.ie/eng/services/yourhealthservice/info/dp/recordretpolicy.pdf>.

Considering the nature of the conditions treated at the NCC, some of which are lifelong conditions, records may be retained for the lifetime of the patient.

Retention periods are subject to change in accordance with any new national guidance or legislative change in this area. This notice will be updated with any changes in this area.

15. Contact details

Should you have any queries about your data protection rights please contact us in the National Coagulation Centre and we will address your issue.

If you wish to raise a complaint on how we have handled your personal information, you can contact us and we will have the issue followed up as per SJH policy.

Our contact details are:

National Coagulation Centre,
St James's Hospital,
James's Street,
Dublin 8.
Phone: 353-1-4162141
Email address: ncc@stjames.ie

Data Protection Office
St. James's Hospital
Dublin 8
Phone: +353 1 410 3021
Email: dataprotection@stjames.ie

16. References

www.dataprotection.ie

www.hse.ie/eng/privacy-statement

www.hse.ie/eng/dataprotectionpolicy

www.gdprandyou.ie