



Data Privacy Notice for Patients and Service Users

How we protect and manage your personal data

Contents

1. Purpose	3
2. The information we process	3
3. Legal basis for processing	3
4. How we obtain information	4
5. Your rights	4
6. Access your health records.....	5
7. Who is the data controller?.....	5
The data controller is the National Haemophilia Director.	5
8. Your information may be used to.....	5
9. What other use is made of your Information.....	5
10. Sharing with third parties	5
11. Transferring information overseas	6
12. How do we keep your records secure and confidential?	6
13. Sharing Information – within the HSE	6
14. Retention period	7
15. Contact details.....	7
16. References.....	7

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.

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, the processing of genetic data, biometric data for the purpose of uniquely identifying a person, data concerning health or data concerning a person's sex life or sexual orientation.

3. Legal basis for processing

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

1. Subsection (b): The processing is necessary for the performance of contract to which the person is a party. This is based on the fact that the government funds the HSE to provide health and social care services to the population and we provide this to the person in fulfilment of that contract
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 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 HSE this official authority is vested through the Health Act 2004 (as amended).

We will only process special categories of personal data where it 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.

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.

If the purpose of the processing is for a reason other than the reasons above, we will seek explicit consent to process your sensitive personal data (referred to as 'special categories' of data under the GDPR).

4. How we obtain information

We may obtain your information from a variety of sources, including 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;
- 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 your health records

You can seek access to your health records by making a subject access request (SAR). You can make a request by contacting 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. Who is the data controller?

The data controller is 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 audits
- 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

Statistical information to other organisations such as the Department of Health, Universities and other research institutions. The HSE 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 /voluntary hospitals or 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 on the basis that anyone to whom we pass it, 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 Protection, Department of Health, TUSLA, the Courts etc., or in an emergency situation to prevent injury to you or 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.

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 named comprehensive care and haemophilia treatment centres are governed by the Data Processing Agreement.

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://assets.hse.ie/media/documents/ncr/HSE_Record_Retention_Policy_V1_101123.pdf

At present there is a local NCC data retention policy in development.

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

16. References

www.dataprotection.ie

www.hse.ie/eng/privacy-statement

www.hse.ie/eng/dataprotectionpolicy

www.gdprandyou.ie