

National Haemophilia System

Patient Information Leaflet



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

NCC

National Coagulation Centre



What is the National Haemophilia System?

Diagnosis and treatment of people and families with haemophilia and other bleeding disorders is provided by the HSE through a combination of specialist treatment centres at HSE managed hospitals and Voluntary hospitals. There are three comprehensive care centres in Cork University Hospital, St. James's Hospital Dublin, and Children's Health Ireland (CHI) at Crumlin and one haemophilia treatment centre at Galway University Hospital.

The National Haemophilia System is an accurate and up to date Electronic Health Record (EHR) for all people with a confirmed diagnosis of haemophilia or related bleeding disorders, on a national basis.

Within each treatment centre, the National Haemophilia System additionally contains healthcare information on people undergoing investigation for bleeding disorders or with a history of thrombosis (clotting).

Who is responsible for the National Haemophilia System?

The HSE is responsible for providing public health and social care services to everyone in Ireland. The HSE (through Galway University Hospital and Cork University Hospital), St James's Hospital and Children's Health Ireland (CHI) at Crumlin are jointly responsible for management and operation of the National Haemophilia System.

What information about me will be collected and processed by the National Haemophilia System?

The National Haemophilia System will collect and process the following types of information

- Your personal details such as name, postal address, date of birth, contact telephone number, next of kin, email address etc.
- Your General Practitioners (GP) name, address and contact telephone number.
- Your pharmacy name, address and contact telephone number.
- Data concerning your health and lifestyle.
- Data concerning any relevant medical treatment and care you may have received in the past.
- List of prescribed and over-the-counter medications that you are currently using and/or was using.
- Medical test results, notes and reports about your health.
- Medical images (for example x-rays, scans etc.) which may have been taken as part of your treatment and care.
- Clinical photographs or videos that may have been taken as part of your treatment and care.
- Personal details of the health care professionals involved in your treatment and care (i.e., names of the clinical team, medical registration number etc.)

What will my information collected and processed by the National Haemophilia System be used for?

The National Haemophilia System will use the information collected for the following purposes:

- To help plan and provide your treatment and care
- To communicate with you during your treatment and care
- To record your treatment and care
- To ensure appropriate information is available if you need to be referred to another health care professional or to another part of the health service
- To populate your patient Portal (if registered for access to the Portal)
- To ensure your concerns can be properly investigated if a complaint is raised
- To help train and teach healthcare students and staff

Summary information may also be used in an aggregate form for the following purposes:

- To help plan and assess current services
- To help plan services for the future

Who will have access to my information stored on the National Haemophilia System and why?

Your information is only shared on a strict “need to know” basis. This means that only the healthcare professionals and administrative staff involved in your care can access it. In some cases, it may also be shared with staff in other healthcare facilities or with other relevant parties when necessary. For example:

- Referrals: if you are transferred from one hospital to another hospital or another type of healthcare facility.
- Second opinion: The health care professionals providing a patient’s treatment and care may wish to seek advice regarding your treatment from other health care professionals based at another hospital or healthcare facility.
- After care: As part of your treatment and care, you may need support at home, such as a visit from a public health nurse or social worker.
- Health related correspondence: your General Practitioner (GP) will receive a summary of your treatment and care.
- Notifiable diseases: Under the Infectious Diseases Regulations 1981, and subsequent amendments, we are legally required to notify the Health Protection Surveillance Centre if a person is diagnosed with a notifiable infectious disease.
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- Order of a Court: We can share your information in response to a court order or a subpoena.

Will my information stored on the National Haemophilia System be kept confidential?

Yes, the HSE (through Galway University Hospital and Cork University Hospital), St James's Hospital and Children's Health Ireland (CHI) at Crumlin are legally obligated under the Data Protection Acts and the EU General Data Protection Regulation (GDPR) to ensure all personal data collected about patients are kept private and confidential.

In order to comply with their legal obligations, Galway University Hospital and Cork University Hospital), St James's Hospital and Children's Health Ireland (CHI) at Crumlin have implemented a series of human, organisational and technological controls to protect all information stored on the National Haemophilia System.

How long is my information kept on the National Haemophilia System?

Your information will only be kept on the National Haemophilia System for as long as is legally necessary. The legal retention period for the different types of medical records is published within the HSE Record Retention Policy and is available on the HSE website at: <https://www2.healthservice.hse.ie/files/275/>

If you have any questions regarding the policy, they should be directed to nrrp@hse.ie

Will information about me kept on the National Haemophilia System be used for Health Research?

Any health research using information from the National Haemophilia System must follow strict data-protection laws and be approved by your hospital and an ethics committee. Some research, like clinical trials, may require your consent. Other work, such as reviewing past treatments, does not. Activities like clinical audits, service evaluations, and quality-improvement projects are not considered health research and do not need ethics approval. Research will be carried out in accordance with the Data Protection Act 2018 (Section 36(2)) (Health Research) Regulations 2018.

<http://www.irishstatutebook.ie/eli/2018/si/314/made/en/pdf>.

What are your Rights?

Under the EU General Data Protection Regulation (GDPR) you have the following rights:

- **Right of access** – you have the right to request a copy of the information that we hold about you.
- **Right of rectification** – you have a right to correct data that we hold about you that is inaccurate or incomplete.
- **Right to be forgotten** – in certain circumstances you can ask for the data we hold about you to be erased from our records.
- **Right to restriction of processing** – where certain conditions apply, you have a right to restrict the processing of your information.
- **Right of portability** – where certain conditions apply, you have the right to have the information we hold about you transferred to another organisation.

If you wish to exercise any of these rights, you can submit a Subject Access Request (SAR), to the following Data Protection Officer (DPO) in the hospital where you are receiving your treatment and care:

Cork University Hospital

HSE Data Protection Officer (DPO) dpo@hse.ie

Galway University Hospital

HSE Data Protection Officer (DPO) ddpo.west@hse.ie

St. James Hospital

St James's Hospital Data Protection Officer (DPO) dataprotection@stjames.ie

Children's Health Ireland (CHI) at Crumlin

- For healthcare records requests. Email: hcr@childrenshealthireland.ie
- For GDPR/data Protection requests. Email: dpo@childrenshealthireland.ie
- For Freedom of information requests. Email: foi@childrenshealthireland.ie

Additional information on subject access requests is available at www.dataprotection.ie

Making a complaint

In the event that you wish to make a complaint about how your personal data is being processed by the hospitals, or how your SAR has been handled, you have the right to lodge a complaint directly with the Data Protection Commission (DPC) at www.dataprotection.ie