Privacy Statement version June 2025

PedNet, the Haemophilia Research Foundation (hereinafter "PedNet," "we," "us," or "our") acts as the data controller under the General Data Protection Regulation (GDPR) and other applicable data protection laws for the personal data collected and used on this website and for the personal data received in our Registry from the participating centres in accordance with our Protocol. PedNet is also the data controller responsible for the personal data processed by PedNet's Registry.

At PedNet, we understand the importance of privacy and we are committed to protecting your personal data with the utmost care. To achieve this, we have implemented appropriate measures to safeguard your information.

This document is regularly reviewed and possibly adjusted. Please note that our website will always reflect the most recent version of the privacy statement.

How to contact PedNet?

If you have any questions or remarks regarding this Privacy Statement or our privacy practices, please contact us at:

- **Mollerusstraat 1**, **3743 BW Baarn**, **The Netherlands**
- **privacy@pednet.eu**

What personal data do we collect and for what purpose? How do we legally process your data?

a) Participants in PedNet's Registry:

PedNet's Registry is a database designed to include children and teenagers with the rare condition of congenital haemophilia A or B. It includes patients who are under 18 and are receiving treatment for haemophilia at one of the specialized health centres ("Participating Centres").

The Participating Centres collect information from patients who meet these criteria based on our Protocol and Collaboration Agreement with PedNet. Each Participating Centre is responsible for gathering your data and acts as the data controller during this process. Once the information is shared with PedNet, PedNet becomes the sole data controller for how it is managed and used within the Registry.

The data collected by your treatment centre is carefully pseudonymized before it's added to the Registry. This means personal details like names or addresses are removed and replaced with a code, so your identity is protected. The information is only used for the specific studies described in the Protocol.

The Registry follows strict standards, including guidelines from the European Medicines Agency (EMA), to ensure it collects the essential data needed for haemophilia research. The following data is used by PedNet:

- **Patient Data**: Month and year of birth, gender, family history, and medical data related to haemophilia are used to maintain accurate records of patients in the PedNet Registry and to understand demographic patterns of haemophilia.
- **Disease-Related Data**: Haemophilia type and severity, diagnosis date, bleeding pattern, surgeries, and quality of life are used to analyse the clinical progression of haemophilia and identify potential treatment outcomes, complications, and quality of life issues.
- **Co-Morbidities**: Data on other diseases that may affect the patient's condition are used to assess the impact of co-morbidities on the treatment and progression of haemophilia.
- **Haemophilia Treatment Data**: Information on treatment type, product used, treatment regimen, start and end dates, and reasons for discontinuation are used to evaluate the effectiveness and safety of haemophilia treatments across different patients. Adverse event data, including dates, associated treatments, seriousness, and outcomes, and its use to monitor and report any adverse events related to haemophilia treatments, ensuring patient safety and regulatory compliance.

If you, as a parent or a guardian, provide consent for the Participating Centre to share your child's personal data, we will receive it securely and treat it confidentially in the Registry. From the age of 12, your child (as patient) will have the option to reconsider its participation in the Registry. The age at which patients must sign consent follows local regulations in your country of residence. The child will receive both written and verbal information about the Registry.

We process your personal data based on your explicit consent (Article 9(2)(a) GDPR). Health data is considered sensitive personal data under the GDPR. Before your child's information is included in The Registry, you (as a parent or guardian) will be given clear, written, and verbal information about how The Registry works and will need to provide informed consent. The signed informed consent form will be retained locally by the participating centres in accordance with applicable privacy and data protection regulations. Your child's pseudonymised personal data will be shared through a secure, web-based Case Report Form (CRF). The purpose of the Registry is to support new studies using the data collected, which will be used for scientific research and/or regulatory purposes, as outlined in the approved study by the PedNet Board.

Once a minor patient turns 18, no additional personal data will be collected, and their data will no longer be actively followed. However, the pseudonymised data collected prior to that age will remain in the Registry for the period required by law and will continue to be used by PedNet for publications. Patients in this category are marked as inactive and included in a separate category within the registry. They may exercise their data subject rights at any time.

Patients and parents/guardians can withdraw or change their initial informed consent at any time. If consent is withdrawn, the data collected up until that point will still be included in the analysis and therefore remains in the Registry.

b) From the study directors, and research partners of Participating Centres we process the following personal information:

- Name, surname, job title, picture, academic professional titles (e.g., MD, PhD), affiliated institution and contact details for professional purposes are published on the website and used to facilitate collaboration, communication, and coordination for research activities and scientific publications.

We process this data based on our legitimate interests (Article 6(1)(f) GDPR). Processing is necessary for facilitating collaboration and communication between PedNet and Participating Centres.

c) From PedNet's management board, scientific advisory council, study staff, and participants in PedNet Activities, we process the following personal information:

- Name, surname, picture, job title and academic background (e.g., PhD, MD) are published on the website, newsletters and publications. This aims to facilitate professional communication and collaboration while showcasing the activities and members of PedNet, including scientific research and publications.

We process this data based on our Legitimate interests (Article 6(1)(f) GDPR). The processing is necessary to coordinate an international collaboration framework involving health centres and physicians treating haemophilia and related disorders. This framework serves as a forum to exchange expertise, encourage collaboration, and support clinical research on haemophilia. It also enables the publication and presentation of scientific research results and supports the overall activities of the PedNet Study Group.

d) From website visitors we collect the following personal information:

- IP address, browser type, location, visit date and time, and pages visited are used to ensure core website functionality, maintain security, and enable basic site operations.

Legal Basis: legitimate interest (Article 6(1)(f) GDPR). We process these essential cookies to maintain the website's performance, enhance security, and ensure a smooth user experience while maintaining GDPR compliance.

How We Collect Your Data

PedNet collects personal data through the following methods:

a) **Directly from you**: We collect personal data when you contact *info@pednet.eu* privacy@pednet.eu, and when you participate in PedNet activities.
b) **Indirectly**: We receive haemophilia patients' data from Participating Centres.

Data sharing with third parties

PedNet shares personal data only with service providers, including the University Medical Centre Utrecht (UMCU) and Castor EDC for the hosting of our Registry, where UMCU acts as a data processor and provides data storage, support, and management services for the Registry on behalf of PedNet.

In the context of PedNet's activities, the pseudonymised data entered into The Registry by the Participating Centres is analysed in studies to generate aggregated results, ensuring that individual patients cannot be re-identified. Participating Centres, regulatory authorities, sponsors and scientific partners (including organisations, institutions or researchers collaborating with PedNet on scientific projects) receive only aggregated or anonymised data from The Registry. They do not have access to personal or pseudonymised patient data. Data is shared based on contractual agreements and for specific purposes, as outlined in The Registry Protocol. All parties with access to data must follow strict data protection and confidentiality agreements.

PedNet may be required by law to share personal data with legal authorities. If this happens, we will do our best to inform you as data subjects.

International Data Transfers

PedNet, receives pseudonymised health data from Participating Centres also located outside of the European Economic Area (EEA) including countries such as Canada, Israel, and Switzerland. For such transfers, PedNet is considered to be a data importer under the GDPR. Any transfers of personal data from these non-EEA countries to PedNet are secured through appropriate safeguards, including adequacy decisions by the European Commission for Israeli & Swiss transfers.

Security of your personal data

The confidentiality, integrity and availability of your personal data is of great importance to us. That is why PedNet takes efforts to appropriately protect your personal data from unauthorised access, alteration, disclosure, or destruction. These data protection measures include:

- **Data pseudonymization**: Patient identifiers are replaced with pseudonymized identification codes known only to the Participating Centres.
- **Access control**: Access to personal data is restricted to authorized personnel only.
- **Data processing agreements**: Agreements with service providers (e.g., UMCU) include specific data protection obligations.

Data Retention

PedNet will retain personal data for as long as necessary to fulfil the purposes for which it was collected, in accordance with applicable laws and regulations.

- **Personal data included in The Registry** will be retained as long as necessary to support studies, including scientific research, and in accordance with legal requirements. This applies to both active and inactive patients (e.g., those over 18). Data may also be retained for purposes such as publications, reporting, or regulatory compliance.

- **Personal data shared on the website** is managed responsibly. PedNet ensures that out-of-date newsletters are regularly removed, and access to journals is restricted to authorized users only.

Once the data is no longer needed for the purposes outlined in this privacy policy, it will be securely deleted or anonymized. Anonymised data may be retained indefinitely for research purposes, as it no longer qualifies as personal data under the GDPR.

Rights regarding your personal data.

In accordance with EU data protection laws, you have the following rights regarding your personal data:

- **Right to Access:** Request access to personal data we hold about you.
- **Right to Rectification**: Request correction of any inaccurate or incomplete personal data.
- **Right to Erasure**: Request deletion of your personal data under certain conditions.
- **Right to Restriction of Processing**: Request a limitation on the processing of your personal data.
- **Right to Data Portability**: Request a copy of your personal data in a structured, commonly used, and machine-readable format.
- **Right to Object**: Object to the processing of your personal data

If you wish to exercise your Data Subject Rights (DSR), you can send us an e-mail at privacy@pednet.eu. Your request will be handled within 4 weeks. We are committed to addressing your concerns and will respond to those in a timely response.

As PedNet holds only pseudonymized data and cannot identify individual patients, we advise you to contact the participating centres directly to exercise your rights. Participating centres are responsible for managing identifiable patient information and can also assist with your request.

If you're not satisfied with our response, you may contact your local Data Protection Authority (DPA) or file a complaint with the Dutch Data Protection Authority here.