



DNDi Privacy Notice for Human Participant Research (HPR) Site Staff Members

I. Introduction

At the Drugs for Neglected Diseases initiative (DNDi) (“DNDi”, “we”, “us”), we take great care in processing personal data. We have chosen to apply a rigorous data protection framework to all site staff members which consists of the Swiss Federal Act on Data Protection (“FADP”) and the European Union General Data Protection Regulation (hereinafter “GDPR”), whilst also complying with the national requirements of your country. This framework is explained to you in this document.

This Privacy Notice for Site Staff Members (the “**Privacy Notice**”) is intended to inform you, as fully as possible, about how your personal data is collected and processed by our organization. It applies to the principal investigator, to all site staff members to whom the principal investigator may delegate or delegates Human Participant Research (“HPR”) related activities (e.g. doctors, whatever their professional specialty, study nurses, study coordinators and study managers, pharmacists, laboratory managers, etc.) as long as they are under the delegated responsibility of the principal investigator (potentially) participating in the HPR sponsored by DNDi (hereafter “**Site Staff Members**”).

II. Why do we process your data?

We process your personal data in relation to the HPR in which you may be or are involved to satisfy our legal or regulatory obligations (e.g. to verify you are adequately trained, experienced and qualified to participate in the HPR) and to establish, exercise or defend legal claims.

To accomplish its mission, DNDi may sometimes need to process your data to pursue its legitimate operational interests: for example, to use and share your personal data with its donors, partners, other consultants and vendors in the scope of its activities; to promote DNDi image and visibility including through social media and networks; to organize business travels through DNDi vendor; monitor DNDi IT equipment use; to prevent fraud and other non-compliant activities, for example those resulting in conflict of interests, to ensure network and information security or to report potential crimes.

We may also process your personal data to pursue DNDi’s legitimate operational interests to communicate with you in connection with:

- Future HPR clinical studies that may be of interest to you, based on your personal data (e.g. the medical field you are active in);
- Events that DNDi is hosting or attending that may be of interest to you, either as a participant or an attendee; and
- DNDi communications (including publications), and/or marketing that may be of interest to you.

If you wish to have more details about the purposes or the legal basis for the processing of your data, you can contact DNDi DPO at dataprivacy@ndi.org.

III. What categories of personal data do we process about you and how do we process them?

DNDi collects and processes the following categories of personal data:

- **Contact details**, such as your name, email, telephone number, work address and, in some cases, private address;
- **Your signature**;
- **Professional details**, such as your place of practice, job title, the medical field in which you are active, CVs, professional qualifications, scientific activities (such as previous HPR

experience, and participation in past or pending research studies), publication of academic or scientific research and articles, and membership in associations and boards;

- Certain **financial information**, such as the declaration of financial interests, if applicable, and other financial information collected for payment and reporting of payments in connection with the conduct of the HPR.

Special Category of personal data:

- **Criminal Record Data:** DNDi may collect information relating to administrative/criminal convictions or alleged unlawful behavior (such as extract from criminal records, debarment or restrictions from practice, professional disqualification) for specific positions unless it is prohibited by local applicable legislation. DNDi will only use such information where the law allows or requires us to do so.

When DNDi is contractually required to share such information (e.g. report to donors), DNDi will anonymize the data using state-of-art methods within DNDi's capacities.

We collect personal data about you from a variety of sources, including directly from you and your institution (e.g. CV/resume), from publicly available sources (e.g. register of licensed medical practitioners in your country), online and other databases and websites, and from any other sources that you provide to participate in HPR and development activities organized by DNDi.

DNDi will only process your personal data as described in this Privacy Notice unless otherwise required by applicable laws and regulations. DNDi ensures that the personal data that we collect about you is adequate, relevant, not excessive and processed for limited purposes.

Note that if you do not provide your personal data, you will not be able to participate in the HPR.

IV. Data sharing with other data recipients and cross-border data transfers

DNDi may share your personal data with others, in connection with the purposes described in this Privacy Notice. In particular, we may make your personal data available to:

- Members of the DNDi international network;
- Regulatory bodies and authorities, e.g. in respect of HPR applications or inspection and/or in the context of product registrations;
- Partners with whom we may collaborate in connection with proposed or actual projects, such as shared research initiatives;
- Our service providers that supply goods and/or services to us, such as legal counsel, auditors and IT service suppliers;
- Our service providers or consultants who supply services on our behalf, e.g. monitoring, medical writing or data management services;
- Auditors or inspectors;
- Insurance;
- Other parties pursuant to a court order, to protect the interests of DNDi, or where otherwise required by law or legal process;
- The public in a limited way through websites, such as the EU clinical trial register and/or www.clinicaltrials.gov, and other websites/databases that serve a comparable purpose to enhance HPR transparency.

Sharing your personal data as described above may involve transferring it to other countries, whose data protection and privacy laws may not be equivalent to, or as protective as, those that exist in your country of residence. Any transfers of Personal Data to DNDi international network members, vendors or suppliers will be done in compliance with the international data transfer conditions that apply under applicable data protection laws, including, where appropriate, through the use of appropriate safeguards, including contractual agreements ensuring the security of your data. You can receive detailed information of recipients and safeguards by contacting DNDi's Data Protection Officer (DPO) at dataprivacy@dndi.org.

V. Will your personal data be used for automated decision-making?

We do not use any automated decision making (including profiling).

VI. What security measures does DNDi take to protect your personal data?

DNDi has put in place appropriate technical and organizational security measures to protect your personal data, which includes protection against accidental or unlawful destruction, loss, alteration, unauthorized access to, or disclosure of your personal data. In addition, we limit access to your personal information to those who are involved in the processing activity(ies) mentioned above, based on their function and role. Upon request, DNDi or its DPO will provide more details.

We have put in place procedures to deal with any suspected data security breach and will notify you and any applicable regulator of a suspected breach where we are legally required to do so, or when it helps to mitigate the consequences.

When DNDi retains a service provider, that provider will be carefully selected and required to use appropriate measures in accordance with applicable law to protect the confidentiality and security of personal data. That provider will only be permitted to process your data on the written instruction of DNDi.

VII. How long do we keep your data?

We will retain your personal data for as long as necessary to fulfil the purposes we collected it for, as required to satisfy any legal, accounting or reporting obligations, or as long as necessary to resolve disputes. For instance, such duration may extend as long as 25 years after the end of a HPR or as per applicable regulatory requirements. We may also keep your personal data for as long as we continue to have a legitimate interest in contacting you regarding future HPR that align with your interests/expertise and other communication purposes, unless you object to such retention.

Once the retention period has expired, your personal data will be either deleted or rendered anonymous. DNDi will make reasonable efforts to ensure the destruction of any existing copy(ies) of your data at third-party recipients.

VIII. Who is responsible for processing the data?

The data controller is Drugs for Neglected Diseases initiative (DNDi), a non-for-profit foundation, member of DNDi, with registered address at 15 Chemin Camille-Vidart, 1202 Geneva (Switzerland).

If you wish additional details about the controller of your data, you can also contact DNDi's Data Protection Officer ("DPO") at dataprivacy@dndi.org.

IX. What are your rights and how can you exercise them?

Under the data protection framework applied by DNDi, you have the following rights in relation to your personal data:

- Right to be informed: you have the right to be adequately informed of the collection of your personal data, including if such data is collected from a third party.
- Right of access: you have the right to obtain confirmation as to whether or not your personal data is being processed and, if so, you may obtain specific information as to the processing(s) of your data. You also have the right to request a copy of all information held about you.
- Right of rectification: you have the right to ask us to rectify, including by completing or amending, all or part of the information held about you which appears incorrect or inaccurate.
- Right to erasure ("right to be forgotten"): you have the right to ask us to delete from our systems any information held about you where there are no longer legitimate grounds to continue to process it.
- Right to object: you have the right to object to the processing of your personal data where we are relying on legitimate interest as legal basis.
- Right to restriction: you have the right to limit the processing of your data under certain specified circumstances.
- Right to data portability: in certain circumstances, you can request to have your personal data returned to you in a structured, commonly used and machine-readable format so that it can be transferred to other data controllers.
- Where you have provided consent for the processing of your data, you have the right to withdraw that consent at any time. Such withdrawal will not affect the lawfulness of the processing that took place before

Please, note that these rights are not absolute and will be assessed on case-by-case basis. If DNDi does not fulfil your request, you will be provided with the reason(s) for such decision. To exercise your rights, contact DNDi's DPO at dataprivacy@dndi.org.

Please contact us if any of the details you have provided change (e.g. name or address).

If you consider that your personal data is not or has not been processed in accordance with the applicable laws, you also have the right to lodge a complaint with the local data protection authority or through other complain mechanism applicable in your country, or with the Supervisory Authority of the country where the DNDi acting as sponsor of the HRS is located.

We would, however, appreciate the chance to deal with your concerns before you approach any such data protection authority or use any other complain mechanism, so please contact us in the first instance by contacting DNDi DPO at dataprivacy@dndi.org. Our DPO can also address any doubt you may have about what data protection authority may be competent.

X. Changes to this HPR Site Staff Member's Privacy Notice

*This Privacy Notice is effective from **15 September 2025**. We reserve the right to change this Privacy Notice at any time (for example, to comply with changes in laws or regulations; our practices, procedures and organizational structures; requirements imposed or recommended by supervisory authorities; or otherwise). Changes to this Privacy Notice shall be applicable on the effective date of implementation. We will communicate any substantial changes to you, where we are required to do so.*