# Rare Horizons: Transition in Action data protection and privacy statement

# Data protection and privacy statement for submissions

Last updated: 02.11.26

This statement explains how personal data is collected, used and protected when your organisation makes a submission to Rare Horizons: Transition in Action, a best practice grant programme funded by Novo.

It covers the online submission form, the eligibility check, assessment by the Rare Horizons Steering Committee, written feedback, and review of recommended submissions by Novo. It also covers the two optional consents in the submission form.

Your use of the Novo website is covered by the Novo privacy policy. Anything relating to your submission is covered by this statement. Please read it before you complete the submission form.

## About Rare Horizons and the Secretariat

Rare Horizons was established and is funded by Novo. Its Steering Committee of healthcare professionals, patient organisation representatives and people living with rare disease assesses submissions and recommends grant recipients. Steering Committee members receive honoraria from Novo.

Intent Health acts as the programme Secretariat. It provides administrative and logistical support: it receives submissions, checks eligibility, coordinates the Steering Committee's assessment and is your contact for questions about the programme. Intent Health does not assess, recommend or approve grant recipients.

## 1. Who is responsible for your personal data

Novo Nordisk Health Care AG ("Novo", "we", "us" or "our") is the data controller. This means we are responsible for deciding how we hold and use personal data about you.

Novo Nordisk Health Care AG, The Circle 32/38, CH-8058 Zurich, Switzerland, CH-101.209.164 Email: privacy@novonordisk.com.

Intent Health processes personal data on our behalf:

- **Intent Health** Ltd, 66 Paul Street, London EC2A 4NA, Company Reg no.: 12873417, as Rare Horizons Secretariat.

Data processors may only use your personal data on our documented instructions and for the purposes set out in this statement. They may not use it for their own purposes.

## 2. What personal data we collect

Most of the information in the submission form is about your organisation and your project, not about individual people. We collect the following personal data:

- **Contact information:** the name, role, email address and telephone number of the project manager, and of any other contact person you name.
- **Declaration information:** the name and role of the person completing the declaration in Section 6, and the date.
- **Conflict of interest information:** anything you tell us in Section 2 about links between people in your organisation and Novo, other healthcare companies or the Steering Committee.
- **Organisation information:** your organisation's name, address, registration number and website, and the names of any partner organisations. In a small organisation, this information may identify individual people.
- **Your choices:** the submission route you select, your consent choices and your confirmation of each declaration.
- **Grant request information:** the amount requested, budget and provisional timetable in Section 5, if you apply for grant funding.
- **Your project description and supporting materials,** including any links you provide.

### What we do not want you to send us

- Information about anyone's health, or any information that identifies an individual young person, patient, family member or member of staff. Please anonymise all case studies, quotes and feedback before you submit them.
- Personal data about anyone under the age of 18.
- Bank details or identification numbers. If your submission is recommended for a grant, Novo will collect these later through the Novo Grant Portal, under its own privacy notice.
- Passwords to your organisation's systems or accounts. Please share supporting materials as view-only links.

If we receive information of this kind by mistake, the Secretariat will delete or anonymise it and it will not be used in the assessment. Submissions must be completed by an adult who is authorised to act on behalf of the organisation.

## 3. How we collect your personal data

We collect personal data directly from you through the online submission form, which is hosted on Microsoft Forms, and through any emails you exchange with the Secretariat.

If you give us details of another person, such as a second contact or a contact at a partner organisation, please let them know and point them to this statement.

## 4. What we use your personal data for, and on what legal basis

| What we use it for | Legal basis |
|---|---|
| To identify and communicate with you about your submission, confirm receipt and check eligibility. | Our legitimate interests in running a fair, transparent and well-administered grant programme (Article 6(1)(f) GDPR). |
| To enable the Steering Committee to assess and score eligible submissions, recommend grant recipients and provide written feedback, and to manage conflicts of interest. | Our legitimate interests (Article 6(1)(f) GDPR). |
| For Novo to review submissions recommended by the Steering Committee, and to invite those organisations to apply through the Novo Grant Portal. | Our legitimate interests (Article 6(1)(f) GDPR). |
| To publish the names of organisations that receive a grant, and the grant value, to meet transparency requirements. | Compliance with our legal obligations (Article 6(1)(c) GDPR) and our legitimate interests in meeting industry transparency codes (Article 6(1)(f) GDPR). |
| To share your submission with Novo so that it can be reviewed, prepared and published in the Rare Horizons Transition Care Best Practice Library on the Novo website, if you agree. | Your consent (Article 6(1)(a) GDPR). |
| For Intent Health, as Rare Horizons Secretariat, to contact you about future Rare Horizons work, if you agree. | Your consent (Article 6(1)(a) GDPR). |
| To report on and evaluate the programme, using anonymised or aggregated information wherever possible. | Our legitimate interests in understanding and improving the programme (Article 6(1)(f) GDPR). |
| To keep the records needed for compliance and audit, and to establish, exercise or defend legal claims. | Compliance with our legal obligations (Article 6(1)(c) GDPR) and our legitimate interests (Article 6(1)(f) GDPR). |

Where we rely on legitimate interests, we have balanced our interests against your rights and freedoms. You can object to this use at any time (see Section 10).

The two consents in Section 6 of the submission form are optional. Whether you give them or not will not affect how your submission is assessed.

### Rare Horizons Transition Care Best Practice Library

If you agree to inclusion in the Library, the Secretariat will share your submission with Novo after the Steering Committee has completed its assessment. Novo will review it and publish your organisation's name, a description of your project and any supporting materials you agree to share. We will not publish the names or contact details of individuals unless you ask us to.

## 5. Who we share your personal data with

| Who | What they receive | Why |
|---|---|---|
| Intent Health, as Secretariat | Your full submission. | To administer the programme, check eligibility, coordinate the assessment and communicate with you. |
| Rare Horizons Steering Committee | Sections 1 to 4 of eligible submissions. They do not receive Section 5 (grant request form), which is not part of their assessment. | To assess and score submissions, recommend grant recipients and write feedback. |
| Novo | Novo, as data controller, may access all submissions. In practice, Novo receives submissions only after the Steering Committee has completed its assessment: in full for those recommended for a grant, and for review and publication for those you have agreed to include in the Best Practice Library. For all other submissions, Novo receives anonymised or aggregated information. | To review recommended submissions through Novo's grant governance process, including review by Novo Legal & Compliance, and to review, prepare and publish Library content on the Novo website. |
| Service providers to Intent Health | Only the data needed to provide their service. | Microsoft, which hosts the submission form and stores data, acting under a written contract as a sub-processor. |
| The public | The name of each organisation that receives a grant and the grant value. Library content, where you have agreed. | To meet transparency requirements, and to share best practice through the Library. |

We may also share personal data where we are required to do so by law, or to establish, exercise or defend legal claims. We never sell your personal data.

Only submissions written in English will be accepted. If you use an AI tool to translate your submission before you submit it, that tool is chosen and used by your organisation, not by Novo or Intent Health. Please do not enter information that identifies an individual into any translation tool, and check that the translation says what you mean. If we receive a submission that is not in English, the Secretariat may ask you to send a translated version.

## 6. Ownership of your submission

Making a submission does not transfer to Novo, Intent Health or the Steering Committee any intellectual property your organisation already owns, such as existing materials, tools or resources you describe or share.

Your submission will be used only for the purposes set out in this statement and in the programme terms in the submission form and guidance. It will be included in the Best Practice Library only if you have agreed to this.

For submissions to this programme, this section applies instead of the section of the Novo privacy policy headed “Use of questions and comments”.

## 7. How we look after your personal data

We have put in place appropriate physical, technical and organisational security measures to protect your personal data against accidental loss and unauthorised access, use, alteration or disclosure. Access is limited to people who need it for the purposes in this statement.

Intent Health, its service providers and Steering Committee members are bound by written contracts that require them to keep your personal data confidential and secure, and to delete or return it when it is no longer needed.

## 8. Transfers outside the EU/EEA

Intent Health is based in the United Kingdom. The European Commission has decided that the United Kingdom provides an adequate level of protection for personal data, so your data can be transferred there without additional safeguards.

Steering Committee members are based in the EU/EEA. Submission data is hosted by Microsoft and stored in the United Kingdom. Microsoft may process some data in other countries, including the United States. Where it does, it uses the safeguards in its data protection terms, including the European Commission's Standard Contractual Clauses and the EU-US Data Privacy Framework.

Novo may transfer personal data within its global organisation, including to countries outside the EU/EEA. We have internal policies in place to ensure an adequate level of protection, wherever in Novo your data is located.

## 9. How long we keep your personal data

- **Submissions not recommended, or not awarded a grant:** up to two years after the end of this grant round, then securely deleted.
- **Steering Committee members' copies:** deleted at the end of the assessment period, or by 31st May 2027
- **Submissions recommended for a grant:** kept by Novo in line with its grant governance and legal record-keeping requirements. The Secretariat keeps submissions only for as long as needed to run the programme.
- **Best Practice Library:** for as long as the Library is available, or until you withdraw your consent.
- **Contact about future Rare Horizons work:** until you withdraw your consent or the Rare Horizons programme ends.

We may anonymise your personal data so that it can no longer be linked to you, and use it for programme reporting.

## 10. Your rights

Subject to applicable data protection law, you have the right to:

- access the personal data we hold about you and receive a copy of it
- have incorrect or incomplete personal data corrected
- have your personal data deleted in certain circumstances
- restrict how we use your personal data, for example while its accuracy is checked

- receive personal data you have provided in a structured, machine-readable format, where the processing is based on your consent
- object to how we use your personal data where we rely on our legitimate interests
- withdraw your consent at any time.

To exercise any of these rights, contact privacy@novonordisk.com. You can also contact the Secretariat at RareHorizonsSecretariat@intenthealth.co.uk, who will pass your request to us. We may ask for information to confirm your identity.

You also have the right to complain to the Danish Data Protection Agency (Datatilsynet) or to the data protection authority in your country.

## 11. Withdrawing your consent

You can withdraw optional consent at any time by emailing RareHorizonsSecretariat@intenthealth.co.uk. We will then remove your submission from the Library or stop contacting you, as relevant. Withdrawing consent does not affect how your submission is assessed, or any use of your data before you withdrew it.

## 12. Automated decision-making

No decision about your submission is made solely by automated means. All eligibility checks, assessments and recommendations are made by people.

## 13. Changes to this statement

We may update this statement. The current version will always be available on the Rare Horizons: Transition in Action webpage, available here.

## 14. Contact us

For questions about this statement or your personal data, contact privacy@novonordisk.com.

For questions about the programme or your submission, contact the Secretariat at RareHorizonsSecretariat@intenthealth.co.uk.

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