Rare Horizons: Transition in Action – Submission Guidance

1. About Rare Horizons

The transition from paediatric to adult care is a pivotal but under supported stage for young people living with a rare disease. It is often fragmented, inconsistent or neglected, leaving young people and their families to navigate unfamiliar systems during a time of significant clinical, social and emotional change, putting them at risk of poorer health outcomes.

Rare Horizons brings together patients, caregivers, healthcare professionals and patient organisation representatives in Europe through a Steering Committee. The Steering Committee provides strategic direction, identifies unmet needs and helps develop practical, patient-centred approaches that address the gaps that can lead to young people becoming disengaged from care, experiencing poor treatment adherence or being lost to follow-up.

2. About the Rare Horizons: Transition in Action Best Practice Grant Programme

Rare Horizons: Transition in Action is a new grant programme, funded by Novo, that provides financial support to patient organisation-led projects to share and help scale real-world examples of effective transition of care for young people with rare disease.

Through this programme, up to five grants of up to €2,000 each may be provided, subject to Steering Committee recommendation and Novo's applicable review and approval processes, to patient organisations whose activities, approaches or resources have successfully supported the transition of care for young people moving from paediatric to adult services, by building readiness, strengthening communication, enhancing confidence, and supporting mental wellbeing.

Eligible submissions will also receive:

Independent feedback	Showcase your work	Rare Horizons Best Practice Library
Every eligible submission receives narrative feedback from the pan-European Steering Committee of clinicians, nurses and patient organisation leaders – giving you concrete input to strengthen your work.	An opportunity to gain exposure for your work and showcase your approach on an international platform, while sharing learning and best practice in transition of care across rare diseases, countries and organisations. Grant recipients will also be invited to an announcement event in 2027, where they will have the opportunity to present their projects.	Eligible submissions will be considered for inclusion in a free-to-access, digital Rare Horizons Transition Care Best Practice Library, regardless of whether they receive funding.
Taking part gives you the opportunity to gain exposure for your work and showcase your approach, while sharing learning and best practice in transition of care across diseases, countries and organisations.		

- *Intent Health acts solely as the independent programme Secretariat and provides administrative and logistical support for the grant programme.*
- *Rare Horizons was established and is funded by Novo. Steering Committee members receive honoraria from Novo. Novo is the programme funder and is responsible for the administration and approval of grants through its established grant governance processes. Following the Steering Committee's recommendations, selected patient advocacy groups will be invited to submit their application through the Novo Grant Portal. All funding decisions remain subject to Novo's independent*

review and compliance procedures, and Steering Committee recommendations do not constitute grant approval.

3. What we are looking for

We are inviting registered, reputable not-for-profit patient organisations to submit existing best practice transition care projects, such as an intervention, tool, service, approach or framework your organisation has already delivered, or is in the process of delivering, that supports transition of care for young people moving from paediatric to adult services.

Strong submissions should highlight the impact of their project for young people and their families, meaningful involvement of young patients in design or delivery (if possible, depending on the condition), and potential to be adapted or scaled across other rare diseases and settings.

Non-exhaustive examples of eligible projects

- Peer-to-peer mentoring programme between young people.
- Workshops dedicated to young people and/or their caregivers.
- Information tools for young people and/or their caregivers.

4. Who can apply

To be eligible for grant funding, organisations must meet all the following criteria:

- Be a registered not-for-profit patient advocacy group (PAG).
- Have demonstrated activity in the field of rare disease transition-of-care optimisation.
- Carry out actions at local, regional or national level.
- Have the legal capacity to receive a donation.
- **Be from any of the following countries:** Ireland, the Netherlands, Lithuania, Denmark, France, Italy and Germany.

Organisations that are not eligible for grant funding include:

- For-profit organisations.
- Healthcare professional organisations or professional bodies. *Where clinicians or hospitals are involved, the application must clearly state that they participate through the PAG and are not the direct grant recipient.*
- Companies or consulting firms.
- Organisations with a political, trade union or partisan purpose.
- Applications submitted by individuals.

We understand that some patient organisations cannot accept funding from a pharmaceutical company. This may be because of the terms of their government or public funding, national rules, or their own policy. We do not want this to stop them sharing good work. If this applies to you, you can still submit your project to be considered for the Rare Horizons Best Practice Library but you will not be considered for a grant, and do not need to complete Section 5 of the submission form. This route is open to registered not-for-profit patient organisations only. It is not open to companies, consulting firms, professional bodies, political organisations or individuals.

5. How submissions are assessed

All eligible submissions will be independently assessed by the Rare Horizons Steering Committee, who will assess submissions against the following criteria:

- **Young person involvement in design and delivery.** Were young people involved, and how?
    - *Exceptions will be made if a cognitive, accessibility, communication or mental health aspect of the condition means young people could not take part in design sessions, complete written feedback, or self-report their experience.*
- **Empowerment.** Does it build confidence, self-efficacy and shared decision-making, and how is that demonstrated/measured?
- **Impact for young people – data and evaluation.** What actually changed, and how was this measured?
- **Capacity for implementation and follow-up.** Can the organisation sustain or evolve the programme beyond the grant?
- **Scalability and transferability.** Could another organisation, in another disease area or health system, adopt this?
- **Equity.** Does it reach young people who experience greater barriers in accessing care? For example, those from low socio-economic groups, or marginalised communities.

Up to five submissions recommended by the Steering Committee will be invited to complete a submission through the Novo Grant Portal, where they will be assessed and approved by Novo global and local Legal & Compliance before any formal grant distribution. Intent Health is limited to administrative support, with no involvement in assessing, recommending or approving grant recipients. Steering Committee recommendation does not guarantee grant approval.

6. Funding

The funding awarded may cover expenses directly related to the project, such as:

- Design and implementation costs.
- Cost of supporting materials.
- Services required to carry out the project.

Not eligible:

- Activities unrelated to the best practice project.
- Hospitality costs (transport, accommodation).
- Promotional, commercial or partisan actions.
- Gifts, promotional items or sponsorship operations.

7. How and when to submit

Complete the submission form on this link: [insert link]. Applications received by any other means will not be considered. Incomplete applications, or those received after the deadline, will not be reviewed.

Please submit in English. If English is not your first language, you are welcome to use an AI translation tool to translate your submission before you submit it. Please check the translation says what you mean. We assess what your project did, not your writing style or the quality of your English.

Key dates

- Submissions open: 10 November 2026

- Submission deadline: 23:59 CET on 21 December 2026
- Steering Committee assessment: January 2027
- Novo review and approval of recommended submissions: January to February 2027
- Announcement event: Q1/Q2 2027, date to be confirmed