



## Key Findings and Recommendations from the Novo Nordisk Haemophilia Foundation's 2022 Grantee Perception Report

Prepared by the Center for Effective Philanthropy

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*In February and March of 2022, the Center for Effective Philanthropy (CEP) conducted a survey of the Novo Nordisk Haemophilia Foundation's (referred to as "NNHF" or "the Foundation") grantees, achieving an 82 percent response rate. The memo below outlines CEP's summary of key strengths, opportunities, and recommendations from the Foundation's Grantee Perception Report ("GPR"). These findings should be interpreted in light of NNHF's goals and strategy.*

*This memo accompanies the comprehensive survey results found in NNHF's interactive online report at <https://cep.surveystats.org> and in the downloadable online materials. The Foundation's full report also contains more information about survey analysis and methodology.<sup>1</sup>*

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### Overview

The Center for Effective Philanthropy is pleased to share the results of the Novo Nordisk Haemophilia Foundation's first survey of its grantees.

- ▶ Overall, grantees hold extremely positive perceptions of NNHF. In written comments, grantees share that working with NNHF is "smooth and effective," an "enriching process," and overall, NNHF "has improved the standard of care of patients with hemophilia."
- ▶ Reflecting these comments, ratings from grantees often place NNHF above the typical funder in CEP's overall comparative dataset. In particular, grantees hold exceptionally positive perceptions of NNHF's impact on their fields, local communities, and organisations, and of their relationships with NNHF. Notably, NNHF is rated among the top of CEP's comparative dataset for its openness to ideas from grantees, and above all other funders for its transparency with grantees.
- ▶ Grantee feedback also indicates opportunities for NNHF to build a deeper understanding of grantees' communities and contexts and to streamline aspects of its grant processes.
- ▶ NNHF's grantmaking approach differs from many of the funders in CEP's comparative dataset, as the Foundation funds research across a wide range of countries with diverse contexts and challenges. What's more, NNHF is often the principal funder of grantees' current work: at the median, NNHF funds two-thirds of its grantees' annual organisational budgets. It is important to keep this context in mind when reviewing the findings from this Grantee Perception Report.

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<sup>1</sup> Throughout this summary, NNHF's ratings are defined as higher than typical when it is rated above the 65<sup>th</sup> percentile in CEP's overall dataset, lower than typical when it is rated below the 35<sup>th</sup> percentile, and typical when ratings fall between those thresholds. Ratings described as "significantly" higher or lower reflect statistically significant differences at a P-value less than or equal to .1.

## Positive Impact on Grantees' Organisations

Grantees provide higher than typical ratings for NNHF's impact on their organisations and its understanding of their organisations' strategies and goals. They write that NNHF's funding has "helped and helps [grantees] to reach [their] goals" and enabled their organisations to "become well organised and fully functioning."

### Long Project-Specific Grants with Opportunity to Expand Scope of Funded Work

- ▶ NNHF provides grants that are similar in size to those at the typical funder in CEP's dataset to smaller organisations (giving grants of 88K CHF, at the median, to organisations with a median annual operating budget of 40K CHF). Additionally, NNHF provides 93 percent of grantees with multi-year grants.
- ▶ Most grantees (95 percent) report that their NNHF funding is restricted to a specific use.
  - In a custom survey question about the type of funding grantees would prefer to receive, approximately half of grantees indicate a preference for unrestricted funding "to better adapt to [their] current needs," while the other half indicate that they prefer restricted funding in order to have "a clear framework and more guidance."
- ▶ When asked how NNHF could improve, the largest theme of grantees' suggestions—posed by ten grantees—involves adjustments to NNHF's grant characteristics. Grantees ask for NNHF to include additional funds in project grants "including helping to pay for staff salary" and to "take into account wages during the implementation of the project." They also ask for NNHF to expand its funding scope, for example by including "the purchase of essential laboratory equipment" in grants.

### Valuable Provision of Non-Monetary Support

A larger than typical proportion of grantees report receiving non-monetary assistance from NNHF during their grant period—64 percent, compared to 40 percent at the typical funder.

- ▶ Nearly all of these grantees describe NNHF's non-monetary support as having had a moderate or major benefit to their organisations or work.
- ▶ In a custom survey question asking grantees what NNHF can do to further support their organisations or local communities, grantees often ask for capacity-building support, including "training for the development and execution of projects," training for "volunteers... to support the project's objectives," and "capacity building on project writing, monitoring, and reporting."



*"The Foundation has shown us where we are and what efforts we still have to make to reach a certain goal. The Foundation has brought about a change in the way we think and work. We are more strategic and rigorous in our approaches."*

## Notable Impact on Grantees' Fields and Communities with Opportunity to Build Contextual Understanding

Grantees hold positive perceptions of NNHF's impact on their fields and local communities, and express their appreciation for the Foundation's impact in their written comments. Ratings and comments also indicate an opportunity for NNHF to build its understanding of grantees' local communities and diverse contexts.

- ▶ Grantees provide higher than typical ratings for NNHF's impact on and understanding of their fields and its impact on their local communities. Relatedly, grantee ratings place NNHF in the top 10 percent of funders in CEP's dataset for its advancement of knowledge in their fields.
  - In comments, grantees appreciate NNHF's commitment to spreading awareness about haemophilia, sharing that its work has led to "improved community awareness/education about

bleeding disorders,” increased “concern [for] haemophilia among the public and the government,” and built “a foundation for enhancing diagnosis, care, and management of this disease.”

- ▶ Grantees rate the Foundation’s understanding of their local communities similarly to the typical funder in NNHF’s custom cohort of other internationally focused funders, but below the typical funder in CEP’s broader dataset. Moreover, ratings for NNHF’s understanding of the social, cultural, and socioeconomic factors that affect grantees’ work are in the bottom 10 percent of CEP’s comparative dataset.
  - Grantees’ comments echo these ratings. The third largest proportion of grantee suggestions—7 comments—relate to NNHF’s impact on and understanding of their local communities. Grantees request that the Foundation “know more about the constraints linked to the context” and better “understand the ground realities and challenges faced by implementing partners.”

“Since we started working in partnership with the NNHF, we have made enormous progress in the care and treatment of people living with bleeding and blood disorders. We have... reached a lot of people through awareness activities and setting up of clinics and centres.... The [national health organization] is also counting on us as a reliable organization to work with in fostering the treatment and care of patients with bleeding/blood disorders.”

“[NNHF could improve by] understanding the politics of each country, taking into account that each region has limits, opportunities and needs.”

## Strong Perceptions of NNHF’s Commitment to Diversity, Equity, and Inclusion

NNHF grantees hold positive perceptions of the Foundation’s commitment and approach to diversity, equity, and inclusion (DEI), providing ratings that place NNHF in the top 15 percent of CEP’s dataset for all measures related to DEI. Grantees agree most strongly that NNHF staff embody a strong commitment to DEI.

- ▶ Grantees also provide higher than typical ratings for NNHF’s understanding of the needs of the people and communities they serve and for the extent to which the Foundation’s funding priorities reflect an understanding of those needs.

“Having their support... [improves] results in the quality of life of little-heard or neglected communities in [our country], undoubtedly generates important opportunities for change, and impacts... the health system.”

## Differences by Respondent Demographics

There are some notable differences in grantee perceptions based on their demographic characteristics.

- ▶ **Respondent Gender:** Grantees who identify exclusively as a woman (n=20) provide significantly higher ratings than those who identify exclusively as a man (n=31) on several survey measures, including for NNHF’s impact on their fields and its transparency.
- ▶ **Respondents with Disabilities:** Grantees who report having a disability (n=11) provide significantly lower ratings than those who do not have a disability (n=39) on many survey measures, particularly across themes of understanding, relationships, and processes.
- ▶ Differences in grantee ratings according to their gender and disability status are independent of grant size, length, and type, organisational budget, the receipt of non-monetary support, and patterns of contact and funding history with NNHF.

## Positive Funder-Grantee Relationships

NNHF receives higher than typical ratings across nearly all measures related to its relationships with grantees, which consists of both funder-grantee interactions and NNHF’s broader communications. In comments, grantees write that they have a “friendly relationship” with NNHF staff who they describe as being “cooperative,” “responsive,” and “very supportive.”

### High-Touch and Productive Interactions

- ▶ Grantees provide ratings that place NNHF in the top one percent of funders in CEP’s dataset for its openness to their ideas about the Foundation’s strategy.
  - Grantee ratings are also higher than typical for NNHF’s responsiveness, approachability, candor, compassion, and respect.
- ▶ NNHF is a high-touch funder; over three-quarters of grantees reporting having contact with their programme manager monthly or more often, compared with about one-quarter at the typical funder. Additionally, 68 percent of grantees—a larger than typical proportion—report receiving a virtual or in-person site visit from NNHF staff during their grant period
  - Grantees who reporting receiving a site visit (virtual or in-person) rate significantly higher than those who do not for NNHF’s impact on their organisations, fields, and local communities. In their comments, grantees appreciate NNHF’s visits with one writing that “physical visits... have a huge impact in understanding our needs and motivating our community.”

### Exceptional Communications

- ▶ NNHF is the highest rated funder in CEP’s comparative dataset for its transparency with grantees.
- ▶ Grantee ratings are also higher than typical for the clarity of NNHF’s communications about its goals and strategy and the consistency of its communications resources.



*“The communication with the Foundation was precise, in an environment of friendliness and respect. Our advisor was continuously interested in our advances and very available to answer our questions.”*



*“We note excellent communication in terms of useful information, perfect interaction that allows us to have a clear idea of what to do throughout the process.”*

## Helpful, Yet Time Intensive and High-Pressure Processes

At the median, NNHF grantees report spending a total of 70 hours on NNHF’s required processes over the lifetime of their grants. This time demand for processes is higher than most other funders in CEP’s dataset. Still, grantees agree more strongly than typical that NNHF’s selection process was an appropriate amount of effort given the funding received.

- ▶ Of note, NNHF grantees report feeling much more pressure than is typical to modify their organisational priorities during the selection process in order to receive funding from the Foundation.
  - Feelings of pressure may, at least in part, be related to the considerable impact of NNHF funding on grantees’ organisations. At the median, NNHF grants support 67 percent of grantees’ annual organisational budgets, compared to just 4 percent at the typical funder.
  - When asked how NNHF could improve, eight grantees suggested improvements to the Foundation’s processes – primarily “simplified” and more flexible systems.

- ▶ Grantees share mixed perceptions regarding NNHF’s reporting process.
  - NNHF is the highest rated funder in CEP’s comparative dataset for the helpfulness of its reporting process. Relatedly, ratings are higher than typical for the relevance of the reporting process and grantees strongly agree that the data they provide in the reporting process is useful.
  - However, ratings are lower than typical for the straightforwardness and typical for the adaptability of the reporting process.
- ▶ When it comes to NNHF’s evaluation process, ratings are higher than typical for the extent to which the evaluation process incorporated grantees’ input in its design and resulted in changes to grantees’ work.



*“I think the processes were clear and the supervision and support constant. Secondary objectives were added on the fly in agreement with the Foundation or some even on its initiative.”*



*“Improvement on project monitoring: a report easier to complete and simple to understand.”*

## Recommendations

Based on this grantee feedback, CEP recommends the Novo Nordisk Haemophilia Foundation consider the following in order to build on its strengths and address potential areas for improvement:

### To reflect on and maintain exceptionally positive perceptions in grantees’ feedback:

- ▶ Celebrate the positive ratings seen throughout the report. Reflect on the practices, approaches, and values that NNHF has used to achieve these results in order to maintain these positive perceptions.

### To address grantees’ feedback about opportunities for greater impact:

- ▶ Consider the feedback from some grantees about a desire for more **unrestricted funding** and funding with a broader scope. If possible, including additional grant funding for **overhead allocations** for expenses such as staff salaries and other indirect costs. Likewise, consider opportunities to provide additional **capacity-building support** to grantees to further strengthen their organisations and communities.
- ▶ Leverage NNHF’s frequent touchpoints with grantees as opportunities to **deepen and communicate the Foundation’s understanding** of grantees’ local communities and contexts.
- ▶ Reflect upon **differences in grantee perceptions based on respondent disability status**, and consider what opportunities might exist for changes to NNHF’s approaches or practices.
- ▶ Continue to review and **streamline aspect of processes**, while maintaining their helpfulness and relevance.

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