

EHDN/MDS(ES) Fellowship Impact Project Report

Executive Summary

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Executive Summary

The clinical fellowship programme in Huntington's disease (HD) was initiated by the EHDN in 2013 and, from 2017, co-sponsored by the EHDN and the European section of the Movement Disorders Society (EHDN/MDS-ES). The key aims of the fellowship programme are to (1) strengthen clinical care in the HD community, (2) motivate and facilitate the training of young professionals working in HD clinical practice, and (3) help establish contacts and opportunities for future collaboration.

The Fellowship Impact Project (FIP) was developed in 2023 to evaluate the impact of the programme on meeting its objectives, identify potential gaps/issues and make data-driven recommendations for improvement. FIP project methodology and data collection were completed in 2023 (July–December), and analysis and reporting were finalised in Q1 2024.

Data were collected from three groups (past fellows, hosts, and the EHDN organisational support team) with high response rates from all three groups (above 90%). Data from past fellows were collected via survey with nominal and open-ended questions, presented in Google Forms and completed online during one-to-one interviews. Data from hosts was collected in the form of four short questions completed by phone or email with the support of EHDN LANCOs and from the EHDN organisational support team via discussion/direct exchange during meetings.

For past fellows, descriptive statistics were utilised for the quantitative nominal questions and thematic analysis was used for the qualitative open-ended responses. Data from hosts and the EDHN organisational support team were carefully considered and synthesised but not formally analysed.

It was clear that a large proportion of past fellows were highly satisfied with what they had learnt from the programme, the opportunities for collaboration, and the impact of the programme on the improvement of their HD practice and care. Hosts appreciated fellows' motivation and enthusiasm. The EHDN organisational support team provided insights into the successes and challenges of programme organisation, placement of the fellows, and administration.

In conclusion, the FIP demonstrated the success of the fellowship programme in providing opportunities for fellows to learn about multidisciplinary HD clinics and contribute to improving care for the HD community in their homelands. The programme will continue to evolve and improve based on feedback.

Recommendations Arising from the Fellowship Impact Project

Data-driven recommendations for further evaluation and considerations for improvement were made as follows:

1. Improve administrative processes – reduce burden on applicants, administration, reviewers and hosts
 - a. Simplify application – reduce uploading multiple documents in email applications and consider online forms (adapted for 2024)

- b. Adapt the application questions to reflect candidate motivation, outline underserved regional needs, individual objectives during the training, and expectations
 - c. Consider Host Support
 - i. Maintain a list of potential hosts (assessed annually)
 - ii. Consider support for administrative tasks (forms, instructions, communication)
 - iii. Host recognition (e.g., at EHDN Plenary meetings)
 - d. Centralised placement of successful candidates – adapted for 2024
 - i. Successful candidates to discuss and agree on a high-level plan for the six-week fellowship with the host
2. Annual evaluation of the programme to regularly assess the effectiveness of adaptations and further needs for improvement
 - a. For fellows completing the programme in future years – adapt the existing Google Forms FIP questionnaire to complete further interviews:
 - i. Semi-structured interviews via Google Forms either to replace the existing Final Report or in addition to the Final Report (note – the Final Report is also a trigger for final payment to the fellow. For ethical and methodological purposes, this should potentially be kept independent from the Google Forms questionnaire)
 - b. To consider obtaining brief feedback/conducting brief interview with hosts
 - c. Obtain feedback from the EHDN fellowship organisational team
 3. Evaluate programme structure and goals
 - a. Explore the potential of expanding the programme – with increasing interest and a number of strong applications from regions with high levels of unmet needs in HD care outside of Europe, discuss broader regional representation of MDS (currently, the programme is conducted only in collaboration with the MDS-ES)
 - b. Clarify what is meant by ‘underserved’, ‘goals’, and ‘eligibility’ relating to the programme requirements
 - c. Consider the development and provision of course materials to fellows and hosts
 - d. Consider minor revisions to the wording on the online application form to ensure good quality information is obtained to assist with the evaluation process
 4. Increase opportunities for collaboration
 - a. Consider visits to additional HD sites as part of the programme (to be agreed through discussion between the host and fellow with the aim of facilitating visits to different clinics and labs within a reasonable distance)
 - b. Encourage fellows to actively participate in EHDN activities, Working Groups, Task Forces
 - c. Develop a community of past and current fellows through regular communications and consider the most effective ways to do this (e.g., What’s App discussion groups) and provide opportunities for future interactions (e.g., at EHDN Plenary meetings)

- d. Encourage current and past fellows to participate in the Fellowship Alumni event at the EHDN Plenary meeting
 - e. Encourage Fellows to become EHDN & MDS members (if not already) in order to have access to regular information on activities and events
5. Re-evaluate the budget (adapted in 2024) and duration of the fellowship
 6. Provide Certificates and recognition to fellows upon completion as a matter of course, thus contributing to their professional development portfolio while enhancing the credibility of the programme