

EHDN/MDS(ES) Fellowship Impact Project Report

Final report

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1. 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

2. Introduction

The Fellowship Impact Project (FIP) was conducted across 2023 and 2024 to assess the overall success of the EHDN/MDS-ES fellowship programme (FP) based on the following objectives:

- Obtain the perspectives of fellows, hosts, and the EHDN organisational team as to how the programme currently meets its aims
- Identify gaps/issues concerning programme delivery
- Make data-driven recommendations for improvement of the programme and future monitoring and follow-up

The clinical fellowship programme in Huntington's disease (HD) was originally set up by EHDN in 2013 and from 2017, co-sponsored by 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.

Initially, fellows were primarily from Europe and had the opportunity to visit a multidisciplinary clinic in Europe. The focus then shifted to some extent to underserved HD regions (i.e., areas that had little or no access to HD expertise), which, in many cases, were outside of Europe.

Applications were invited for fellowships, and potential applicants were assisted in making contact with a potential multidisciplinary host clinic in Europe. Successful fellows then spent six weeks in a multidisciplinary clinic where they had the opportunity to experience various clinical and research aspects of HD, acquire knowledge on the latest research and clinical trials as well as see how a multidisciplinary clinic works in practice. Six fellowships were normally granted per year, but sometimes an additional one or two were awarded, depending on the breadth of the applications and recommendations by the Evaluation Committee comprising of both EHDN and MDS staff and representatives. If fellows were awarded similar points and agreed to be suitable for the programme, an additional one or two fellows were occasionally granted. In 2023, in support of Ukraine, an additional fellow from Ukraine was selected and sponsored by donations collected during the registration process for the previous EHDN plenary meeting.

After several years (and despite a break due to COVID-19), the programme continues to be very successful. The most recent call (2023–2024) attracted the highest number of applications to date, representing interest from all over the world. The programme continues to gain momentum, and therefore, an evaluation of how it is meeting the stated aims was undertaken.

An interim analysis was carried out on data collected up to September 2023 to inform the 2024 EHDN/MDS-ES programme (announced at the end of 2023). Based on the results from the interim analysis, adaptations were made in four key areas that had been indicated as challenging:

- For potential fellows, the application and evaluation processes were adapted to provide:
 - Online application process with pre-checked applications for eligibility (completeness and relevance of documentation/attachments; qualifications and registrations; age/years post-specialisation; languages; home institution recommendation)
- Centralised placement of selected candidates to ensure that:
 - A list of potential hosts was available for the EHDN FP team
 - Applicants would not need to arrange host acceptance to be eligible
 - Discussions regarding hosts took place after the evaluation
- Increased funding for fellows
- Modification of eligibility instructions to provide equal opportunities for all geographical regions was ensured by:
 - Including European candidates within the general definition of ‘underserved HD care’ along with specific aspects of ‘underserved care’

This report presents the full analysis of the collected data from the EHDN/MDS-ES FIP. The results provide valuable insights into the overall impact of the HD fellowship programme and will help to ensure that it continues to meet its intended goals.

3. Project Description

The FIP was initiated and developed by the EHDN and underwent a consultation process internally with the EHDN Think Tank (TT) and with MDS-ES. Both the MDS and EHDN were regularly updated on project progress. The overall Project planning and timelines are presented in Appendix 1 (i.e., Figure 1).

Impact was assessed across the three fellowship programme objectives to measure success to date and to inform future improvements. Archived records and reports from past fellows and hosts were used to provide context in the planning of the evaluation and survey methodology.

Data were collected from programme participants (past fellows), organisers, and hosts via structured interviews, questionnaires, and direct outreach. Both quantitative and qualitative data were analysed as fully as possible.

The impact of the programme was evaluated at three levels:

- Past fellow: This assessed the impact of the programme on the careers and professional development of past fellows, including their clinical knowledge and skills, their professional network development, and overall satisfaction with the programme. An additional element of interest was whether the fellow continued to be involved in HD care as a measure of the longer-term impact of the programme
- Host: This briefly assessed the satisfaction of the host institutions with the programme, such as the transfer of knowledge (two-way) and skills (to the fellow), the development of new collaborations, and the overall contribution to the HD community.

- Operational: This assessed the overall implementation of the programme, such as the criteria, application and selection process as well as the implementation of the programme.

The key data sources were:

- Semi-structured interviews: In-depth interviews were conducted with 22 past fellows spanning multiple geographies, specialities, and completion years. The interviews allowed quantitative and qualitative insights into participant experiences. Open-ended questions collected data on the goals of fellows in undertaking the programme, the main learning outcomes that were achieved, the opportunities that were offered for collaboration, perspectives on the length of the programme, and the appropriateness of the budget provided. The final open-ended questions invited any further comments and recommendations for the improvement of the FP.
- Host interviews/questionnaires: Short questionnaires were completed by 18 fellowship hosts, gathering host perspectives
- Organisational feedback: Supplementary perspectives on programme operations were contributed via consultations/feedback/discussions with the EHDN organisational support team.

In summary, the evaluation synthesised findings from past fellows, hosts, management, and the EHDN organisational support team. This enabled a comprehensive overview of multi-stakeholder data, capturing information on programme impact, value, and improvement opportunities.

4. Data Collection

Past Fellows

The main data were collected via survey with nominal and open-ended questions, presented via Google Forms and completed online. To ensure comprehensive feedback on the open-ended questions, semi-structured interviews were conducted and audio recorded to allow transcripts to be saved for analysis purposes. A team of six interviewers with expertise in the FP and interview methods conducted the interviews from August to October 2023. Interviewers were instructed to ensure a standardised approach according to the objectives of the evaluation. All previous fellows were contacted to check their availability, and 22 agreed to an interview. In addition, four more past fellows completed the online questionnaire without doing the interview.

Remote ~45-minute semi-structured interviews were conducted via Zoom. Interviewers and fellows were allocated pragmatically according to their availability and native language (where possible). With the advance permission of participants, interviews were recorded and then transcribed to enable detailed analysis. A standard Google Forms online questionnaire was completed by the interviewer (mainly during the interview) to help ensure that core questions linked to the Programme objectives and the overall implementation of the programme were considered. The option was also provided for additional information to be noted. After the interview, the Google Forms questionnaire response was forwarded by email to the fellow to check and confirm. The Google Forms questionnaire is provided in Appendix 2.

Regular debriefing sessions were held with the interviewers to ensure consistency in interview techniques and data collection, address any challenges, and reinforce objectives.

The interviewed fellows represented different years of the programme and geographical areas, allowing a range of experiences to be captured.

Host Interviews

Feedback was gathered from 18 hosts from a possible total of 23. Some of the hosts had retired, had moved on, or were not available for other reasons. All the hosts asked gave feedback. Some of the participating hosts hosted multiple fellows across the years of the programme, allowing longitudinal insights. Data collection took place in the form of four short questions completed by phone or email. The email template with questions to hosts is provided in Appendix 3.

Organisational Feedback

Feedback was gathered in the form of discussions about various aspects of the programme, including implementation, application process, application evaluation, and selection of hosts.

5. Data Analysis

Fellow Feedback

Descriptive statistics were utilised for quantitative questions of Google form answers of past fellows. There were two types of quantitative questions – binominal questions and those rated on a scale of 1–6 (with 1–3 being negative and 4–6 being positive). Open-ended/qualitative questions were analysed using thematic analysis as per the established approach of Braun and Clarke (2006) to support and verify the quantitative questions and identify common patterns. This was performed using the Google Forms data in an Excel format, with reference to the transcripts where required for clarification.

The thematic analysis consisted of six steps (Braun & Clarke, 2006):

1. **Familiarisation:** overview of all data
2. **Coding:** development of short labels relating to themes and patterns in the data
3. **Generating themes:** re-focus on the analysis at the broader level of themes
4. **Reviewing themes:** review and refinement of the emerging themes
5. **Defining and naming themes:** formulating the *meaning* of each theme
6. **Write up:** report preparation

The first three steps were performed by one reviewer (CD), and steps four and five were verified by three reviewers (CD, FM, JB).

Host and Organisational Feedback

The less structured approach to gaining the perspectives of hosts and organisation representatives involved a variety of different means for data collection. While this maximised the flexibility and ease of data collection, formal qualitative analysis was not appropriate. Nonetheless, the inspection of the feedback resulted in useful insights, which are synthesised in the results section.

6. Results

Data were collected as follows:

- Past fellows – 31 past fellows were identified who completed the programme from four continents (Europe, Asia, Africa, and South America), representing 21 countries. There were 26 responses to the Google survey, four of which were completed without an interview. All questions were answered by all applicants unless they were no longer working in the field of HD (n=3 past fellows)
- Interviews – 18 hosts participating in the programme
- Feedback from the EHDN organisational support team

Response rates were:

- Past fellows – overall response, including interview and/or completion of the Google Forms questionnaire was 84% (26 participants out of 31); 26 completed both Google Forms and/or both Google Forms and/or interviews
- Hosts – the 18 hosts who were contacted responded, providing a response rate of 100%
- EHDN organisational support team – feedback was provided mainly from the lead responsible for the programme, and additional information was gathered from the specific staff in the areas of their involvement, e.g., financial and country-specific topics

Fellows: Descriptive statistics

This section presents the quantitative analysis of the data obtained via the Google Forms questionnaire. A comprehensive picture requires that findings from the thematic analysis are also taken into account, given that the binominal questions had clarifying comments. All figures for the quantitative data are presented in Appendix 4.

Continuous Engagement in HD

Over 88% of past fellows continue to be involved in HD activities (Figure 2 in Appendix 3). A description of their activities at the time of interview is presented in Table 1. The three past fellows who had changed their career path at the time of the interview reported being involved in MS, CVD, and general neurology due to personal circumstances, commuting difficulties, and professional opportunities.

Table 1. Overview of past fellows' current professional HD activities

HD topic	Countries/Regions Involved	Key Activities and Focus Areas
Clinical Care and Management	Chile, Spain, Bulgaria	Management of HD patients through clinics and specialised programmes.

		Neurological evaluations, treatment, and multidisciplinary care
International Collaborations and Projects	Egypt, Ukraine, Armenia, Colombia, Brazil, etc.	Collaborative efforts for research, training, and setting up clinics Participation in Enroll-HD
Research and Epidemiological Studies	Venezuela, Armenia, Ukraine	Collection of epidemiological data. Genetic testing and research projects Validation of assessment tools and demographic studies
Professional Training and Education	Egypt, Bulgaria, Israel	Initiatives for training local physiotherapists Educational efforts and multidisciplinary team coordination
Community Support and Advocacy	Bulgaria, Brazil, Dominican Republic	Leadership roles in national HD associations. Counselling roles Advocacy work in the Dominican Republic
Enroll-HD Study Participation	Colombia, Ukraine, Canary Islands	Involvement as investigators in the Enroll-HD study
Occupational Therapy and Physiotherapy	Egypt, Israel	Collaboration for expert visits and online courses Physiotherapy resources and training
Specialised Clinics and Centres	Ukraine, Canary Islands, Israel	Setting up specialised clinics for Movement Disorders and HD Coordination of a national HD centre
Leadership and Involvement in HD Associations	Bulgaria, Israel	Leadership roles in the Bulgarian HD Association Coordination of the national Israeli Huntington Centre

Improvement of Care in HD

The impact on improvement clinical care was assessed via a rating scale from 1–6 using questions about the direct impact on clinical practice and the indirect impact on professional development in the HD field (see Figures 3 and 4 in Appendix 4). More than 90% of the fellows felt the FP provided direct benefit in improving their clinical practice (providing ratings from 4–6, with half seeing it as a significant improvement with a rating of 6). Two participants provided a rating of 3. All past fellows believed that the FP provided an opportunity to advance in their professional development in the HD field (rating 4–6, with more than half evaluating it as 6, i.e., as having high impact).

Knowledge and Collaborations in HD – Fellows’ Goals

Fellows outlined a varied set of learning objectives centred around HD. Their aims encompassed acquiring knowledge about Enroll-HD, understanding HD clinical procedures, exploring diverse treatment options, and gaining insights into genetic counselling. Establishing connections with professionals in the field, learning different approaches to HD treatment, and understanding the unique challenges of late-stage HD were also important goals. The overarching theme was a commitment to comprehensive learning and expertise development in the field of HD.

All fellows were satisfied that the programme met their training objectives (providing ratings 4–6), with the majority achieving their goals (83% providing the highest rating of 6, evaluated as completely meeting their personal goals) as well as the opportunity for collaborations (see Figure 5 and 6 in Appendix 4).

Examination of the data on the opportunities for networking during the fellowship placement provided more diverse results, and although the majority provided positive responses (with ratings 4–6), 20% of participants chose the lower range in this regard by rating 4 (see Figure 7 in Appendix 4).

Programme Satisfaction

Satisfaction from the programme was measured on two levels – organisational and support. These questions received top ratings, reflecting very high satisfaction with the quality of the mentorship (Figure 8 in Appendix 4), followed by EHDN organisational support (Figure 9 in Appendix 4); instructions and application materials (Figure 10 in Appendix 4). More variability arose on the question regarding the organisation and structure of the programme at the host (Figure 11 in Appendix 4), but was mainly positive with ratings 4–6, with the majority (61.5%) giving the highest rate of 6. One participant scored this in the negative range with a rating of 3.

When asked whether they would recommend the programme to others, all participants reported as highly likely, with 25/26 providing a rating of 6 and 1 participant rating 5 (Figure 12 in Appendix 4)

Programme Duration and Budget

The most polarised responses related to the duration of the programme and the necessary budget (Figures 13 and 14 in Appendix 4). Approximately 60% of the participants reported that the duration of the 6-week programme was too short, and 50% felt the budget was not sufficient to cover their living costs.

Fellows: Thematic Analysis

Goals of Fellows

The thematic analysis showed that the goals of the fellows in undertaking the programme could be defined as Advancing HD Knowledge and Gaining New Perspectives and Opportunities. The theme of Advancing HD Knowledge encompassed specific aspects of HD care and specialities (e.g., genetic counselling) in the HD field, as well as research and multidisciplinary working. The wish to advance knowledge for the purpose of improving HD care in their own country of residence was noted by several of the fellows. When discussing topics relating to Gaining New Perspectives and Opportunities, several fellows pointed to the importance of gaining experience of HD care in a different country, and the value of opportunities for collaboration and networking within the HD field.

Learning Outcomes

Participants were asked what they considered to be their most important learning outcomes arising from the fellowship. Here, the theme of Increased Knowledge reflected the content reported by fellows in terms of goals, such as gaining new knowledge in relation to research, HD assessment and HD care. A second theme, labelled Implications of HD, emerged from the fellows' responses. Several fellows reported developing a better understanding of the ethical aspects of HD (such as genetic testing) and the broader impact of HD on family members.

Opportunities for Collaboration

While a small minority of fellows reported that opportunities for collaboration had been limited, within the theme of Professional Development, many reported involvement in the EHDN and EHDN Working Groups, working with other professionals, and multidisciplinary working. The theme of Collaborative Outputs reflects the involvement of fellows in writing papers for publication, establishing research links, and developing future plans for collaboration, visits, research, and so on.

Duration of Fellowship

Many fellows reported that the fellowship had been too short, although some reported being satisfied with the overall length. The overarching theme arising from the responses was the Need for Flexibility in terms of duration as well as how and when the fellowship could be completed. These fellows pointed to the need to balance other commitments, such as family.

Adequacy of Budget

The majority of fellows reported that the budget they had been allocated was inadequate, and some viewed the budget as an 'assistance' rather than living costs. Several fellows had

opted to stay in accommodation provided by their host or family, which had helped considerably, and others reported using their own funds. The theme labelled Insufficient Budget, therefore, reflects that the budget as it stands was not sufficient to cover the living costs of fellows unless assistance with accommodation was made available.

Further Recommendations

Finally, fellows were asked if they had any further recommendations for the improvement of the FP. Under the theme of Programme Management, several respondents suggested that improved structure, training, allocation processes/host planning, as well as increased budget and duration would be helpful, consistent with previous responses. In terms of the theme of Wider Experience, fellows suggested that additional opportunities such as meeting other past and current fellows, as well as the opportunity to develop lasting collaborations during the fellowship, would be beneficial.

Feedback from Hosts

Visual inspection of the responses to the open-ended questions confirmed that the fellows were overwhelmingly willing, interested, and eager to learn. Likewise, several hosts confirmed they had found the experience to be positive and had remained in contact with the fellow. Hosts also noted that useful additions to the programme for future years could include an information booklet for hosts (outlining expectations, key contacts, and so on). Hosts also noted that the fellowship could be burdensome in terms of bureaucracy (e.g., form filling and various permissions), and, finally, not necessarily provide the clinical experience that fellows might be seeking. Finally, practical limitations such as funding and housing for fellows and the costs for hosts were mentioned by several hosts as being problematic.

Feedback from the EHDN Organisational Support Team

Some feedback regarding the organisational aspects of the application process pointed to challenges associated with increasingly large number of applications, submissions by email, resource intensive to organise applications and hosts were organised in most cases in advance of applications. This meant that the EHDN staff often had to help find a suitable host before the application was submitted, which was very resource-intensive. Expectations were also raised on the side of the host as well as the fellow, after which the fellow was often not selected during the evaluation process. For example, in one case, the applicant did not make a submission for the fellowship after the host clinic had been organised, plans made for accommodation, and so on.

It was reported that significant resources are needed to manage the programme as it currently stands. This process could be improved to streamline activities and increase efficiency. Nonetheless, regular contact has been maintained with selected fellows over the programme cycle (from application to completion of fellowship, reporting, and so on).

Organising hosts for fellows was often quite difficult at short notice. While local Lancos were often able to assist with this, the lack of suitable and affordable local accommodation for fellows was raised by hosts. Potentially, it was suggested that the timing of the fellowship could be adjusted to increase the chances of finding suitable local accommodation. In particular, the budget for the fellowship became an issue when fellows were searching for

accommodation. Also, flights from outside Europe are often very expensive, and higher travel expenses of over €1000 have to be agreed upon in advance.

The EHDN operational support team was in regular contact with MDS during the programme cycle of each FP. As agreed, the majority of administrative processes were undertaken by EHDN, with reviewers from MDS-ES mainly assisting in the selection process and the dissemination of information through established global networks, which has increased the number of applications.

As noted above, the feedback from fellows indicated a wish to develop or maintain contacts with other fellows. From an EHDN operational support perspective, it would be important to ensure that fellows become members (if not already) and that they continue to be involved in the network. This would ensure that the groundwork set during the fellowship phase would bring lasting benefits to the work of the EHDN and the HD community more broadly. Finally, after completion of the fellowship, it was reported that fellows often asked for a certificate from either EHDN or the host clinic in recognition of their learning.

7. Discussion

To recap, the 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.

This is achieved by giving early career healthcare professionals the opportunity to deepen their knowledge about the disease and treatment options within a well-established HD clinic. As HD is a rare disease, the same opportunities for learning are not as readily available as for more prevalent diseases, such as Alzheimer's and Parkinson's disease. For this reason, the EHDN initiated the FP to encourage the sharing of knowledge and experience from multidisciplinary HD clinics, such as Enroll-HD.

After several years of the programme, the FIP was successfully completed over nine months (July 2023–March 2024), representing six months of data collection followed by three months dedicated to data management, translation (where required), analysis and reporting.

The response rate was very high from all three groups participating in the study. There are several possible explanations for this, not least the involvement in the strong and well-organised HD community, high professional retention rates in the HD field (as evidenced by the vast majority of past fellows remaining in HD clinical practice), and the chosen project methodology.

It is encouraging to see that despite career changes or personal circumstances, most fellows remained connected to HD work. Fellows were also satisfied with the support provided by the EHDN, which is more than likely due to the timely follow-ups and regular contact on their journey from application-selection-hosting by the HD clinic. All queries were dealt with, and any other issues or queries were addressed as they arose.

For the past fellows, the majority reported being 'highly satisfied' with the programme and meeting their professional learning objectives, consistent with the results from the thematic

analysis, which pointed to the demonstrable benefits of advancing HD knowledge and gaining new perspectives and opportunities.

Overall, the feedback indicated that the programme is well received by both hosts and fellows. In light of the feedback, some changes have already been incorporated into the FP and further changes will be made in advance of the next programme round.

The thematic analysis of the interviews with past fellows confirmed the value of the fellowship in terms of meeting their professional development and learning expectations. Where opportunities for collaboration and networking were available, these had been welcomed. This is an aspect that could usefully be built upon in future years.

Perhaps most critically, there were clear indications that both the fellowship budget and duration of the fellowship required re-evaluation. Although the descriptive statistics indicated that 50% were satisfied with the budget, in the comments to that question, it was identified that the positive answers were due to the additional support the fellows received either from hosts providing free accommodation or friends and family. Some fellows also did not expect the budgets to fully cover costs but rather viewed it as an assistance budget. Further insights into administrative challenges were obtained from hosts and EHDN operational support team feedback. The administrative burden of the application procedure, evaluation of candidates, placement of fellows, accommodation issues, and budget were indicated by all participating groups. This was exacerbated due to the much-welcomed success of the programme. As application numbers continue to increase, there is a further need to streamline procedures and overall programme planning.

In considering these results, it may be beneficial to look at how other similar programmes are conducted. One such programme is that of Clinical Fellowships offered by the European Academy of Neurology and the MDS Visiting Trainee Grant Program. Consideration may be required about budgets and other factors that could increase the success of the fellowship programme.

In conclusion, the FIP has led to specific recommendations based on the feedback obtained from fellows, hosts, and the EHDN organisational team. These are summarised in the final section below.

8. Recommendations

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

9. Summary of Actions Taken for the 2024 Programme Based on the Interim Analysis

1. Application process
 - a. Electronic application
 - b. Adapted review process
2. Centralised placement of successful candidates
 - a. Application requirements adapted,
 - b. List of potential hosts created
 - c. Engagement of LANCOs in supporting host identification
3. Budget – adapted
4. Regular communication activities
 - a. Link fellowship placement with attendance at Plenary meeting
 - b. Encourage all fellows (and applicants) to become EHDN members

10. Acknowledgements

We are very grateful for the valuable contributions from past fellows, hosts, EHDN and MDS staff, and everyone who supported this evaluation.

11. Appendices

Appendix 1. Project Overview

Figure 1. Project overview and timelines



Appendix 2. Google Forms Questionnaire – Past Fellows

EHDN/MDS-ES Huntington's disease (HD) clinical fellowship evaluation questionnaire

June 2023

Dear Past Fellows,

Many thanks for your interest in helping us to evaluate the EHDN/MDS Huntington's Disease fellowship programme. Please take a few moments to complete a brief survey. Your feedback will help us improve the programme's impact and support for future fellows. By continuing, you are agreeing to participate in the survey. Thank you in advance for your time and contribution.

1. Are you currently engaged or planning to be involved with HD community in clinical or research activities?

Yes/No

If "No", then this is the end of the survey, thank you for your time.

2. Please provide a brief overview of your current HD professional activities:

3. What were your goals during the fellowship programme? What did you want to achieve?

4. Did the fellowship programme change your clinical practice in any way in providing clinical care for individuals with Huntington's Disease?

1=Not at all, 6=Significantly

5. On a scale of 1 to 5, please rate how well the fellowship programme met your training goals?

(1 = Not at all, 6=Completely)

6. What were the top 3 clinical learnings following the fellowship? not mandatory

7. Did the fellowship programme provide opportunities for collaboration with other professionals in the field of HD research and care during or after the programme?

Yes/No

If yes, please provide examples:

8. Do you feel the Fellowship Programme had an impact on your professional development in the HD field?

Please rate on a scale of 1 to 6. (1 = No impact, 6 = High impact)

1	2	3	4	5	6
---	---	---	---	---	---

9. Fellowship programme Satisfaction Levels:

a. How satisfied were you with the structure and organisation of the fellowship programme at the host? Please rate on a scale of 1 to 5. (1 = Very dissatisfied, 6 = Very satisfied)

1	2	3	4	5	6
---	---	---	---	---	---

b. Please rate the quality of the mentorship provided during the fellowship.

1= Very dissatisfied, 6 = Very satisfied)

1	2	3	4	5	6
---	---	---	---	---	---

c. How satisfied were you with the networking opportunities provided during the fellowship programme? (1 = Very dissatisfied, 6 = Very satisfied)

1	2	3	4	5	6
---	---	---	---	---	---

d. How satisfied were you with EHDN staff support from application to arrival at the host? (1 = Very dissatisfied, 6 = Very satisfied)

1	2	3	4	5	6
---	---	---	---	---	---

e. Please rate the quality of the instructions and application materials provided for the fellowship.

(1= Very dissatisfied, 6 = Very satisfied)

1	2	3	4	5	6
---	---	---	---	---	---

10. How likely are you to recommend this programme to others?

1= Not at all likely, 6 = Very likely)

1	2	3	4	5	6
---	---	---	---	---	---

11. Was the timeframe (6 weeks) adequate for the fellowship?

- Yes
- No, please comment

12. Was the budget for the fellowship adequate to cover costs?

- Yes
- No, please comment

13. Any suggestions or recommendations for improving the fellowship programme?

Thank you for your time and feedback! This input will help us to improve the structure and overall impact of the fellowship program

Appendix 3. Host Feedback Request

Email template

Dear Host,

Many thanks for your dedication and commitment to the EHDN/MDS Fellowship programme over the years. We are now conducting an impact review of the overall fellowship programme and would like to request some short feedback from you as host please.

Would you be willing to have a short call with one of our team to answer a few brief questions?

This would be very helpful in improving the next phases of the fellowship programme. Thanks in advance.

Brief questions:

- How did you experience (in general) the willingness and interest of the fellows to learn about Huntington's Disease?
- Are you still in contact with the past fellows? Do you have any collaborative projects?
- Are there any areas where we can make improvements to enhance the hosting experience?
- Would you be willing to host a fellow for the upcoming phase of the fellowship programme? (Fellowship placements during 2024)
- Any other comments?

Appendix 4. Google Forms Questionnaire Responses: Past Fellows

Figure 2. Percentage of past fellows who continued to be involved in HD

1. Are you currently engaged or planning to be involved with HD community in clinical or research activities?

26 responses

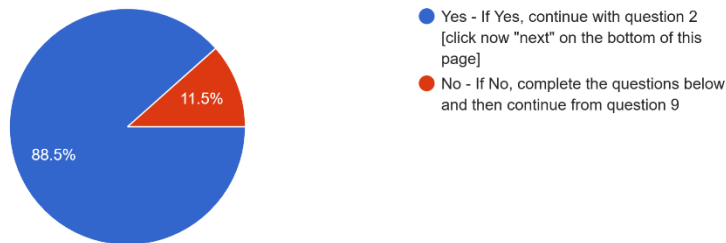


Figure 3. Improving clinical practice in HD

4. Did the fellowship programme change your clinical practice in any way in providing clinical care for individuals with Huntington's Disease? Please rate on a scale of 1 to 6.

23 responses

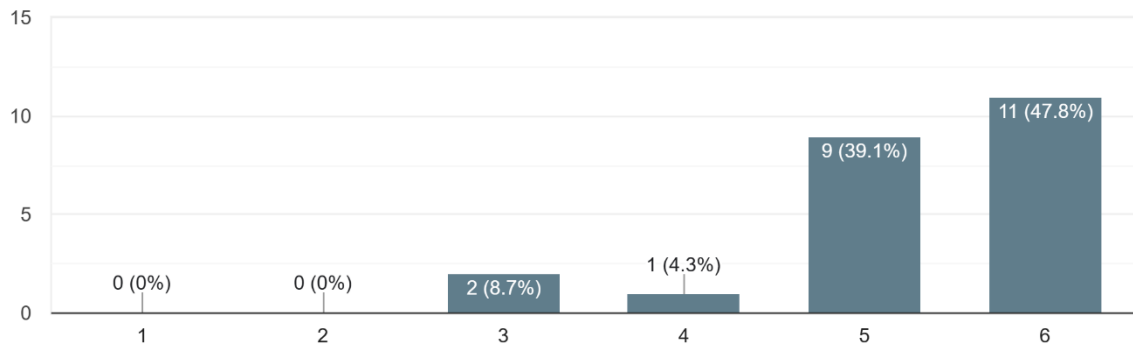


Figure 4. Positive impact on professional development in HD

8. Do you feel the Fellowship Programme had an impact on your professional development in the HD field?

23 responses

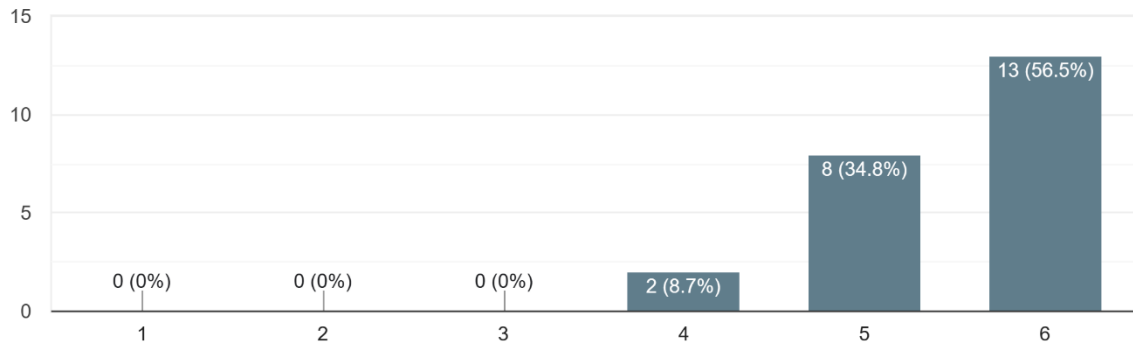


Figure 5. Meeting professional development goals

5. Please rate how well the fellowship programme met your training goals?

23 responses

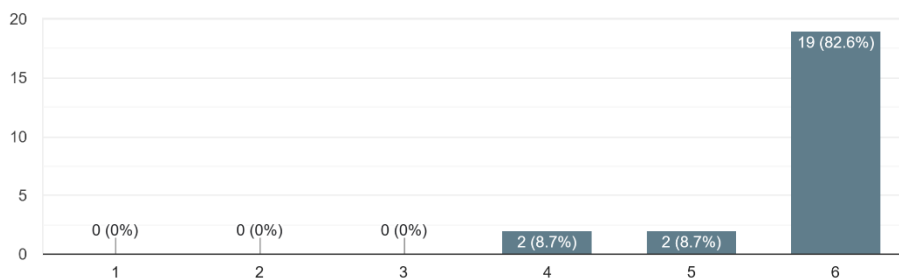


Figure 6. Opportunities for collaboration during the fellowship

7. Did the fellowship programme provide opportunities for collaboration with other professionals in the field of HD research and care during or after the programme?

23 responses

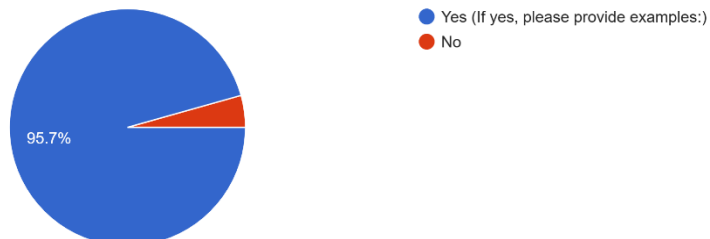


Figure 7. Opportunities for networking during the fellowship

c. How satisfied were you with the networking opportunities provided during the fellowship programme?

26 responses

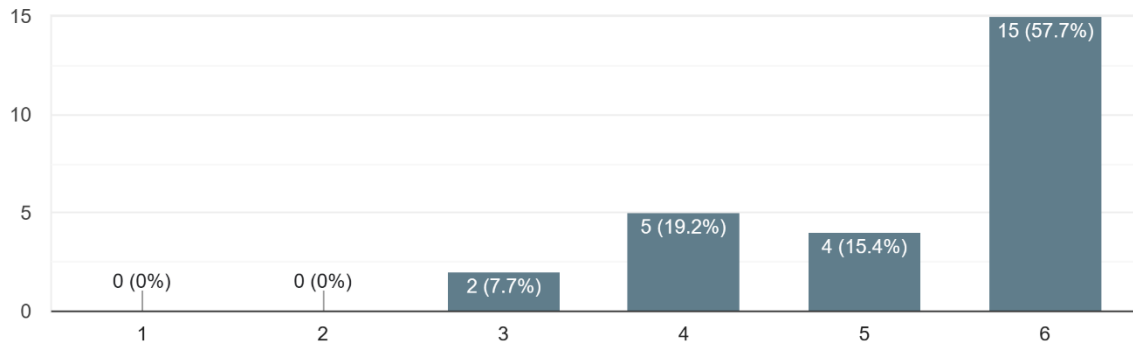


Figure 8. Quality of mentorship during the programme

b. Please rate the quality of the mentorship provided during the fellowship.

26 responses

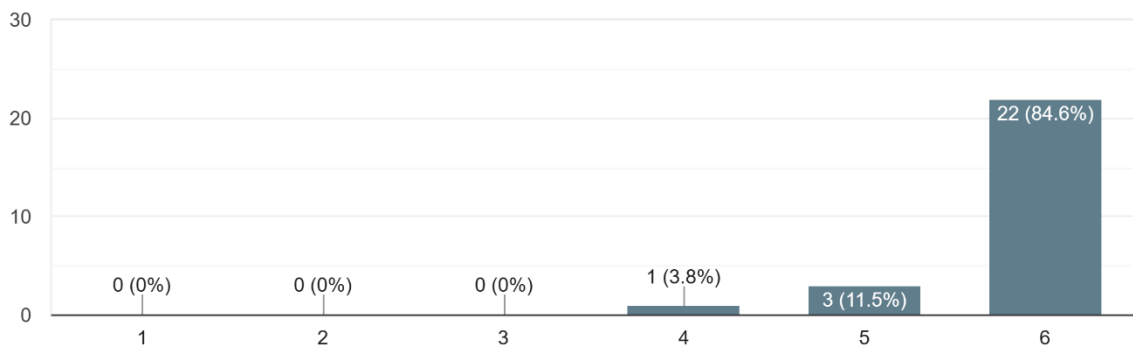


Figure 9. EHDN staff support to fellows

d. How satisfied were you with EHDN staff support from application to arrival at the host?

26 responses

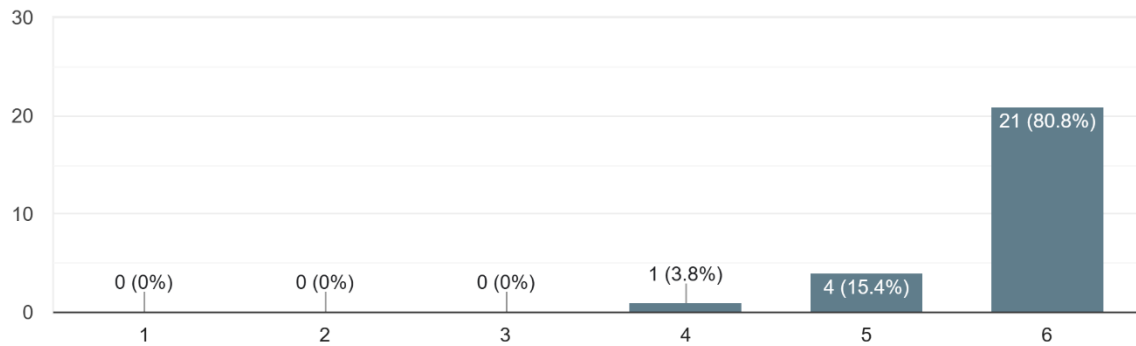


Figure 10. Guidance and application material

e. Please rate the quality of the instructions and application materials provided for the fellowship.

26 responses

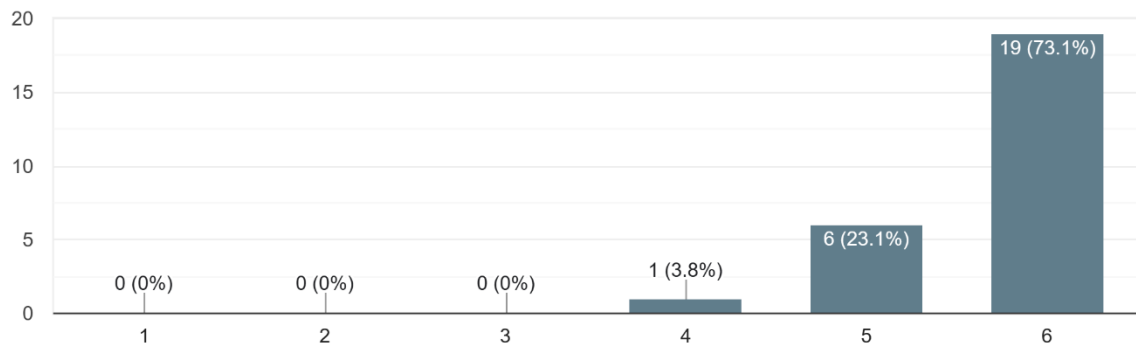


Figure 11. Overall structure and organisation of the fellowship programme at the host

a. How satisfied were you with the structure and organisation of the fellowship programme at the host? Please rate on a scale of 1 to 6.

26 responses

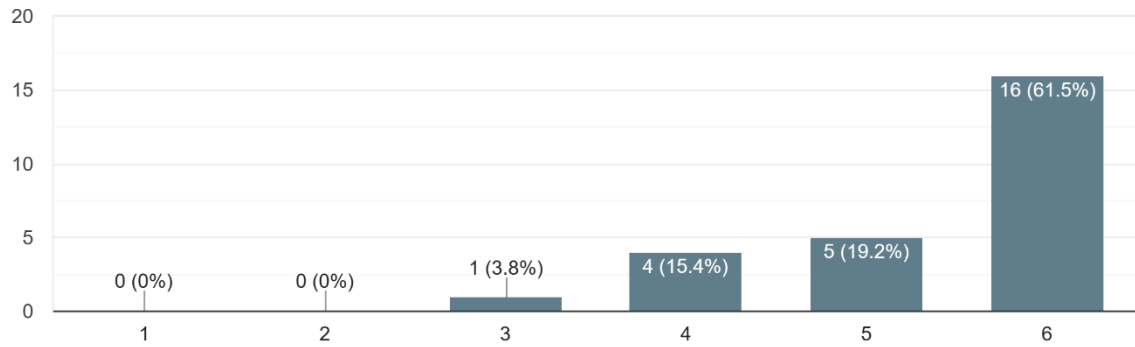


Figure 12. Recommendation of the programme

10. How likely are you to recommend this programme to others?

26 responses

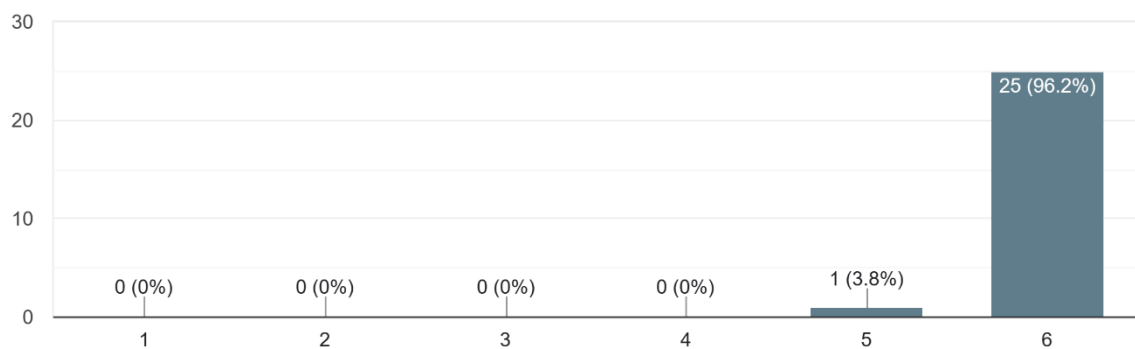


Figure 13. Duration of the fellowship programme

11. Was the timeframe (6 weeks) adequate for the fellowship?

26 responses

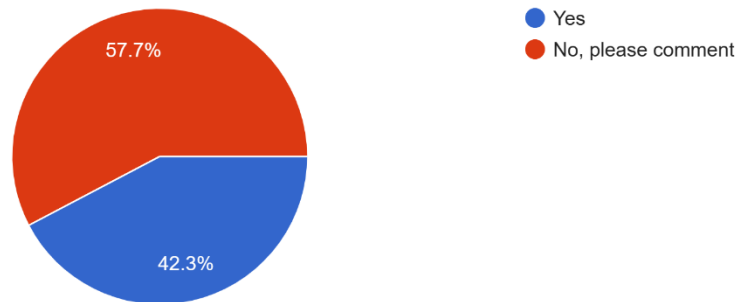


Figure 14. Budget requirements

12. Was the budget for the fellowship adequate to cover costs?

26 responses

