

An overview of the Huntington's Disease population and specialist services in the UK (England, Scotland, Wales and Northern Ireland)

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What does this study mean for the Huntington's disease community?

The UK Huntington's Disease Network (UKHDN), Huntington's Disease Association (HDA), Scottish Huntington's Association (SHA) and Roche Products Ltd (RPL) are collaborating to map how HD services in the UK are delivered and resourced at a local and national level. This will provide evidence to support dialogue with decision makers to help secure healthcare resourcing and funding where needed.

Conclusion

This is the first study to provide a local and national picture of the HD patient population and HD services across the UK. Overall, there is variation in how HD specialist services are delivered in the UK. The data derived from this study provides evidence for the HD community and can be used to support current and future resource needs of HD services.

INTRODUCTION

Objective: The aim is to provide an analysis of specialist services for Huntington's Disease in the UK.

- Huntington's Disease (HD) services throughout the United Kingdom (UK) have grown organically and are embedded in different healthcare specialties: psychiatry, neurology and genetics.¹⁻⁴

- There is currently no national picture of how these services are delivered at a local level or indeed how many people with HD (PwHD) are treated in each service, which means we cannot compare the current service provision to a consensus view of quality care.
- This project was undertaken to map the current organisation, resources and funding of HD services so that we can quantify any differences across the UK and explore future resource needs.

METHODS

- This was a mixed methodology study with existing specialist HD services identified through desktop research.
- All identified services were invited to participate through the UKHDN.
- Data was collected on each service via a cross sectional questionnaire hosted on an online platform and a follow-up web-assisted telephone interview.

- The quantitative questionnaire included questions on: current HD service provision, patient pathway, resource, funding and support for patients.
- The qualitative phase consisted of semi-structured interviews led by the HDA or SHA and continued until data saturation was achieved.
- This project was delivered through a partnership between the UKHDN, the HDA, the SHA and RPL.

RESULTS

- 31 HD specialist services were identified and invited to participate: 18 in England, 10 in Scotland, 2 in Wales and 1 in Northern Ireland.

Table 1. Overview of HD specialist services in the UK (n=27)

Type of centre	Freq	Percent
Mental Health Trust	7	26
Tertiary referral hospital	7	26
Genetics & Neurology	4	15
District General Hospital	3	11
Other	3	11
Third sector provider eg. SHA	2	7
Rehabilitation service	1	4
Clinical lead for the HD clinic		
	Freq	Percent
Neurologist	10	37
Psychiatrist	8	30
Other ¹	5	19
Geneticist	4	15
Services		
	Freq	Percent
Outpatient clinics	26	96
Outreach in the community	20	74
Telemedicine	19	70
Inpatient beds	7	26
Satellite clinics	7	26
None of the above	1	4

¹Other included: clinical neuropsychologist, neuropsychiatrist and consultant nurse

- The cross-sectional survey included 27 of these 31 services: 15 in England, 10 in Scotland and 2 in Wales, with 3 services in England and 1 in Northern Ireland not participating.

- Over half of specialist services were led by a mental health trust (n=7) or tertiary referral hospital (n=7), and the majority had a neurologist (n=10) or psychiatrist (n=8) as clinical lead (**Table 1**).
- The majority of services has outpatient clinics (96%) and many had outreach services (74%) and inpatient clinics (26%)
- Likewise, the majority of services were involved in at least one clinical study (78%) and all services involved in research participated in Enroll-HD.

Table 2. Overview of the HD population at HD specialist services (n=27)

HD clinics	Average	Min	Max
Number of PwHD managed at clinic (last 12 months)	173	5	950
HD clinics per month	13	0	50
Number of PwHD seen per clinic	6	0	12
Proportion of PwHD in each Shoulson-Fahn stage			
	Average	Min	Max
Pre-manifest	18	0	50
Stage 1-2	24	0	50
Stage 3	32	0	60
Stage 4-5	26	0	100

Note: PwHD, People with Huntington's Disease. The service managing 5 PwHD does not currently have an HD clinical lead however they are planning on developing the service so has been included for completeness.

- The average number of PwHD managed by each service per year was 173, ranging from 5 to 950 across the UK (**Table 2**).
- On average across services 18% were pre-manifest HD, 24% were stage 1-2 HD, 32% were stage 3 HD and 26% were stage 4-5 HD.

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Abbreviations

HD, Huntington's disease; HDA, Huntington's Disease Association; PwHD, People with Huntington's Disease; RPL, Roche Products Ltd; SHA, Scottish Huntington's Association; UKHDN, UK Huntington's Disease Network.

References

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Notes

Enroll-HD is a global longitudinal, observational study of Huntington's disease.



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