

Research Report

An Overview of Specialist Services for Huntington's Disease in the United Kingdom

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Abstract.

Background: Huntington's disease (HD) is a rare inherited neurodegenerative disorder characterized by complex evolving needs that change as the condition progresses. There is limited understanding about the organization of HD clinical services and their resourcing in the United Kingdom (UK).

Objective: To understand the organization and resourcing of specialist HD services for people with HD (PwHD) in the UK

Methods: This cross-sectional study collected quantitative data via an online survey, and qualitative data via telephone semi-structured interviews. Descriptive statistics were used to describe quantitative outcomes, and qualitative results were analyzed using content analysis.

Results: A total of 31 specialist services for HD were identified. Of the 27 services that completed the online survey, 23 had an active multidisciplinary team of healthcare professionals (HCPs) and were led primarily by a mental health trust (26%) or tertiary referral hospital (26%). Specialist services offered outpatient clinics (96%), outreach in the community (74%), telemedicine (70%), inpatient beds (26%) and satellite clinics (26%). Many services indicated that their capacity (ability to see patients as often as needed with current resources) was difficult, with some services reporting more difficulty at the early or later stages of HD. Key resourcing gaps were identified with access to facilities, HCPs and referral networks.

Conclusions: This research highlights the variation in organization and capacity within individual HD services as well as current resourcing and gaps in access that influence this capacity. Further research should be done to understand the impact of service organization and current resourcing gaps in access on the quality of care provided for PwHD in the UK.

Keywords: Huntington's disease, health services organization, health services capacity, United Kingdom, NHS

INTRODUCTION

Huntington's disease (HD) is a rare inherited neurodegenerative disorder characterized by complex evolving needs that change as the condition pro-

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gresses. Symptoms include abnormal involuntary movements, behavioral disturbance, cognitive dysfunction, and psychiatric disorders, and a range of somatic symptoms that have a comprehensive negative impact on an individual's physical and mental well-being, and lead to long-term disability and, ultimately, death [1–3]. The prevalence of HD in the United Kingdom (UK) has increased over recent decades [4], with an estimated prevalence of 12.3 cases per 100,000 people [5]. There are currently no approved treatments to successfully halt or impede the progression of HD, and the aim of clinical management is to alleviate the burden of symptoms and maintain and improve function and quality of life [6].

In recent years, promising research has been conducted that offers the potential for meaningful disease-modifying therapies to treat HD. Previous studies have highlighted the importance of understanding how healthcare services are organized and delivered across HD services to provide insight into the delivery of HD clinical services and quality of care [7]. In light of this, international guidelines for the management of people with HD (PwHD) and their families have been developed to standardize care and provide scientifically supported recommendations for the treatment of HD [8, 9].

However, specialist services throughout the UK have grown organically and are embedded in different specialties, including neurology, psychiatry, and genetics. In addition, little is known about the organization of clinical services for HD and there is currently no national picture of how these services are organized, resourced, or funded at a local level, nor is it known how many PwHD are treated in each service. This is particularly important when trying to understand areas of good practice and enabling an equality of service for PwHD. As such, there is a growing need to compare the current service provision with a consensus view of quality care, and to assess the capability of specialist services to accommodate future treatment developments in the UK.

This mapping study was undertaken to obtain a comprehensive understanding of the organization and resourcing of specialist HD services for PwHD in the UK.

MATERIALS AND METHODS

Study design and study population

This was a mixed methodology study of HD specialist service centers across the UK, with data

collected via a quantitative survey hosted on an online platform, with a follow-up web-assisted telephone interview providing qualitative insights. This study was conducted in collaboration with the UK Huntington's Disease Network (UKHDN), Huntington's Disease Association (HDA), Scottish Huntington's Association (SHA), HCD Economics, and Roche Products Ltd. (RPL). Specialist services for HD were identified through desktop research and all services were invited to participate through the UKHDN.

The cross-sectional survey included 36 questions relating to the organization of HD service, the patient population, current resource within the HD clinic (facilities, personnel, and referral networks), funding, and the future patient pathway. This paper reports on the organization of the HD service, patient population and current resource within the HD clinic/funding only. Those who agreed to participate were contacted for the follow-up qualitative research, which consisted of one semi-structured interview¹ for each service, led by the HDA or SHA. The interview guide was developed based on the results of the cross sectional survey in order to expand on responses in the survey data. Data were collected between July and November 2021.

Data analysis

For the quantitative analyses, descriptive statistics were used to explore and describe the outcomes. For the qualitative analyses, each interview was transcribed, and a content analysis performed on each script, i.e., codes derived directly from the text data were developed into mutually exclusive categories and then merged into key themes. Coding and data analysis was performed using NVivo software (Version 12). Interviews continued until data saturation (no new themes emerging) was achieved.

Results from the quantitative survey are reported under four headings: identification and overview of services, identification of PwHD population, capacity at HD specialist services and key gaps in relation to capacity with access to facilities, HCPs and referral networks and also reported in Tables 1–3. These gaps were also identified as key themes in the qualitative phase.

The insights from the qualitative interviews are shown using quotation marks in separate boxes and

¹ Interview topic guide is available from the corresponding author upon reasonable request.

next to each quote we indicate the role the respondent has within the HD service.

RESULTS

Identification of specialist services for HD

A total of 31 specialist services for HD were identified through desk research (England 18, Scotland 10, Wales 2, and Northern Ireland 1) of which 27 centers completed the online survey (quantitative phase), primarily by a clinician (15) or nurse (5). The follow up interview (qualitative phase) was completed in 23 centers: 13 in England, 8 in Scotland and 2 in Wales, and interviews were mainly with a clinician (13) or nurse (7).

Overview of specialist services for HD

The main characteristics of these specialist services are summarized in Table 1. Services were led primarily by a mental health trust (26%) or tertiary referral hospital (26%), with clinical leads predominantly comprising neurologists, psychiatrists, and geneticists. Other clinical leads were neuropsychologists, neuropsychiatrists, or HD specialist nurses.

Of the 27 services that completed the online survey, 23 had an active multidisciplinary team (MDT), comprising common HCPs that included neurologists (63%), research nurses (63%), psychiatrists (56%), and HD specialist nurses (48%) (Table 2). MDT meeting frequency varied from none at all (15%), to weekly (41%), monthly (19%), or more than monthly (15%).

Majority of specialist services offered outpatient clinics (96%) and many also offered outreach in the community (74%) and telemedicine appointments

Table 1
Overview of HD specialist services in the UK

Type of organization, n (%)	n (%)
Mental Health Trust	7 (26)
Tertiary referral hospital	7 (26)
Genetics and Neurology	4 (15)
District General Hospital	3 (11)
Other	3 (11)
Third sector provider, e.g., SHA	2 (7)
Rehabilitation service	1 (4)
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Clinical lead for the HD clinic	
Neurologist	10 (37)
Psychiatrist	8 (30)
Other	5 (18)
Geneticist	4 (15)

Table 2
Overview of healthcare professionals (HCPs) working regularly as part of a multidisciplinary team (MDT, n = 27)

HCP	n (%)
Neurologist	17 (63)
Research nurse	17 (63)
Psychiatrist	15 (56)
HD specialist nurse	13 (48)
HD specialist employed by HDA	13 (48)
Geneticist	12 (44)
Researcher	9 (33)
Speech and language therapist	9 (33)
HD specialist employed by SHA	8 (30)
Occupational therapy	7 (26)
Physiotherapy	6 (22)
Social worker	5 (19)
Other*	5 (19)
Dietician	3 (11)
Nurse	2 (7)
Dentist	1 (4)

*Other HCPs include clinical psychologists, support workers, neuropsychiatrists, and research fellows.

(70%). Fewer services offered inpatient beds (26%) or satellite clinics (26%).

Specialist services were primarily funded through hospital or health board (National Health Service, NHS) budgets, with this channel accounting for 53% of funding on average, followed by national funding (e.g., NHS England) (18%), and clinical trials or research grants (12%).

Population served by HD specialist centers

The average number of PwHD managed annually by each specialist service was 173, ranging from 5 to 950, reflecting the wide variation in the populations served. The distribution of PwHD in each stage ranged from an average 18% pre-manifest HD, 24% Stage 1-2 HD, (Total Functional Capacity (TFC) score between 13 and 7), 32% Stage 3 HD (TFC score between 6 and 3) and 26% Stage 4-5 HD(TFC score between 2 and 0).

Capacity at specialist service

Specialist services reported on their capacity defined as ability to see patients as often as needed with current resources. Specialist services generally reported that they had the capacity to see PwHD as often as required, with some differences observed across services and disease stages. However, some services reported that it was difficult to see patients across all HD stages: from premanifest (7%) up to late

Table 3

Capacity to see PwHD as often as the clinic needs to, by disease stage ($n = 27$)

	Premanifest	Stage 1-2	Stage 3	Stage 4-5
Difficult	2 (7)	4 (15)	2 (7)	5 (18)
Adequate	15 (56)	13 (48)	13 (48)	15 (56)
Easy	9 (33)	10 (37)	12 (45)	6 (22)
Don't know	1 (4)	0 (0)	0 (0)	1 (4)

stage manifest (18%) (Table 3). Two services reported difficulty in seeing premanifest patients as often as they needed due to these patients being unaware of services available, or ambiguities around which service should manage patients undergoing the transition from symptom-free to manifest HD. Capacity at HD specialist services was further explored in relation to current resourcing within the HD specialist service. Key gaps were reported with access to facilities, HCPs and referral networks during the quantitative phase and these gaps were further identified and expanded on in the qualitative analyses.

PwHD access to facilities

Specialist services reported whether they had adequate access to facilities available to manage all PwHD at their service, with 8/27 (30%) services reporting inadequate access to rooms, and 3/27 (11%) services reporting inadequate access to both tests and/or equipment. During the qualitative phase, services expanded on their lack of access to facilities:

"Clinic spaces are extremely difficult to get hold of at times unless you have a block booking" (Psychiatrist)
 "There is just a lack of rooms . . . the neuro outpatient department is small; the rooms are small . . . But there's such a demand on the clinic room space throughout the week." (Nurse)
 "If we had more rooms we could do more but there's such a demand on the room space, the clinic room space, throughout the week that it's been very difficult to find additional space to do anything different." (Nurse)

PwHD access to HCPs

Difficulty accessing HCPs both internally (i.e., the HD specialist service) and externally (i.e., the various auxiliary services required by PwHD) was the most frequently reported gap that affected capacity in specialist services for HD. The majority of specialist services reported difficulty accessing HCPs. Within the services (internally), many reported lim-

ited access (i.e., services that reported less than 25% of patients that require access receive it) to neurologists, psychologists, psychiatrists, HD specialist nurses, counselling, and support for caregivers where necessary. Outside the service (externally), many services reported limited access to community mental health support. Again, access to these HCPs varied by service and location.

Access to HCPs was further discussed during the qualitative interviews, which supported the key gaps in access identified in the quantitative data and highlighted gaps in mental health support (both within the HD service and in the community) and access to HD specialist nurses:

"Psychological support, difficult to access . . . General psychiatry, if PwHD need proper input from a psychiatrist, it's difficult." (Neurologist)
 "Mental Health Services almost zero. I mean, we have a really bad record of patient access to those services." (Psychologist)
 "Mental health is a massive unmet need within the clinic" (Psychologist)
 "We don't have enough clinical specialist nurses, which I think underpins the whole service; that's absolutely essential." (Neurologist)
 "I think that if we had a specialist nurse and somebody who had a full job plan for HD, then we would do much more" (Geneticist)

PwHD access to referral networks

HD specialist centers reported on the biggest barriers when referring HD patients either internally or externally to the service. The largest barrier reported was due to availability of HCP/finding an HCP that specializes in HD/finding a HCP in close proximity (i.e., resourcing) (46%). However, lack of resourcing was not the only challenge for PwHD accessing relevant HCPs. Willingness of HCPs to manage HD patients when available (16%) and reluctance of patients to be referred (8%) were also identified. Only 5% of specialist services reported that there were no barriers to referring patients.

Insights from the qualitative research showed how a lack of understanding of HD from HCPs outside of the HD service, often led to referrals (particularly mental health and social care) being rejected, and PwHD falling between services:

Likewise, reluctance of patient to be referred was also identified as a key theme for lack of access during the qualitative interviews. Some services reported that PwHD lack insight into their illness and do not have the ability to seek support due to cognitive symp-

“The clinicians aren’t aware of HD and what they can do to help . . . because they don’t know what to do, they refer back to the specialist service.” (Psychologist)
 “I think sometimes . . . we are frustrated that patients seem to fall between services . . . do they need adult social care, or they need specialist mental health social care” (Nurse)
 “There are some community mental health teams that won’t or don’t or aren’t commissioned to see patients with organic brain diseases like Huntington’s Disease and so then there is a huge gap in the services that are offered to patients under those circumstances.” (Geneticist)
 “People with HD will often get excluded from local mental health teams.” (Neuropsychiatrist)

toms, or are in denial about their illness. Equally, they may feel the services cannot offer any support, or are not tailored to manage HD, especially community mental health support, which is not set up to manage PwHD:

“People who deny or don’t want to know. Perhaps it’s in their families, they know they’ve got a few early signs, but they don’t want to engage because they’re frightened.” (Psychiatrist)
 “If there is psychology [mental health services] it’s not tailored to HD, so people might engage and think this is just not relevant; I don’t feel they’ve got the expertise and feel that it’s not right for them or people are rejected.” (Psychologist)

Lack of access to referral networks either due to availability, willingness of HCPs or patient reluctance was identified as a large gap in the current provision of HD services. Care Coordinators, while not explicitly asked about during the interview, play a vital role in organizing between clinics and also, being the main point of contact between different HCPs and patients sometimes:

I think sadly a lot of services across the country don’t have a Care Coordinator and a full MDT who are devoted as HD specialists; I think we really excel in that” (Psychologist)
 “And the specialist nurse’s role in a sense is to coordinate services and directly put in the, you know, towards the correct services. So, the outreach services would very much depend on the needs of the patient, I guess.” (Neuropsychologist)

DISCUSSION

This study provides new insights into the organization, capacity, and current resourcing of specialist services for HD in the UK and identifies unmet need in the provision of healthcare to PwHD. To our knowledge, this is the first complete overview of the number and location of HD specialist services in the UK. In addition, this is the first overview of the PwHD pop-

ulation served by HD specialist services in the UK. This study found that there was considerable variation in the number of PwHD managed annually at each specialist service reflective of population density and geographical area covered by the service which is in line with variation in prevalence across the UK reported previously [10]. This study found that there was considerable variation in the number of PwHD managed annually at each specialist service reflective of population density and geographical area covered by the service which is in line with variation in prevalence across the UK reported previously [10].

These data provide valuable insight into the landscape of HD specialist centers in the UK and can be used to inform future resourcing and planning decisions.

Overview of specialist services in the UK

Specialist services for HD in the UK are primarily led by a neurologist or psychiatrist, and most specialist services have an active MDT with regular meetings. A key finding from this study is that specialist services varied greatly in their organization and service provision. A multidisciplinary approach to HD is strongly promoted in the literature [9, 11–13], and, while this is evident at most specialist services in the UK, the types of HCPs present in each MDT varied. More than half of specialist services had a neurologist, research nurse or psychiatrist in the MDT, but other HCPs were varied and less common, such as, physiotherapists, occupational therapists, dieticians, and social workers.

The impact of these variations on patient care is not clear, but further research is required to understand the impact of these variations on quality of care and, where possible, standardize access across specialist services to ensure that services have the capacity to care for PwHD at all stages of disease.

Capacity at HD specialist centers

Capacity (defined as ability to see patients as often as needed with current resources) varied between specialist services and disease stage. Access to facilities, HCPs and referral networks were identified as key gaps affecting capacity.

Limited access to HCPs was particularly apparent, specifically accessing mental health professionals and HD specialist nurses. 46% of HD services reported “availability of a HCP or finding a HCP that specializes in HD in close proximity” to be a barrier

in accessing HCPs. Indeed, resourcing of HCPs in a system of finite resources is a key challenge across the NHS [14]. In addition, HD is a complex condition that crosses the boundaries of neurological, psychological, and behavioral issues, and requires multiple HCPs to manage the complexities as well as auxiliary services such as occupational therapy (OT), speech and language therapy (SALT), or social services [11]. As before, resourcing and availability of HCPs differed by service and region and some services reported lack of capacity to treat PwHD as often as the clinic needs which suggest the need to standardize access of care across the UK.

Although resourcing was a key issue for access to HCPs, accessing referral networks was considered an equally large challenge. The willingness to treat PwHD was identified as a key barrier to accessing referral networks (16%) and varied greatly, with evident reluctance from some HCPs who lack an understanding of how to treat HD, which leads to rejection of referrals and PwHD ending up in a constant referral loop, unable to access any services, which is detrimental to their care. The willingness to treat was particularly apparent with mental health referrals, and was the greatest reason for lack of access to mental health services for PwHD.

The mental health burden in HD is well documented [15–18], with depression, anxiety and suicidality being common. A previous study also found access to psychological services for PwHD across the UK to be scant and unequitable [19]. The literature highlights the need to ensure provision of adequate mental health and preventive services for PwHD to alleviate the burden of HD [20]. However, this study highlights the gap in access around mental service provision to HD patients, as many general and community mental health services are not commissioned to treat patients who have organic brain disorders meaning PwHD can be continually referred out. Likewise, reluctance of patients to be referred (8%) was also identified as a barrier to accessing referral networks. The fundamental nature of HD means that PwHD have difficulty accessing or engaging with services due to cognitive impairment that leads to lack of awareness of their condition [21]. Many interviewees discussed these groups, such as those who lack insight, or groups that are disadvantaged in their access to clinical review because of language or cultural barriers. PwHD who drop out of the HD service in late-stage HD (i.e., transfer to residential facilities) should also be considered. This research only briefly explores this topic and further

research is required to better understand the groups who do not access HD services and how services can be adapted to better reach these groups.

This study shows that some HD specialist services in the UK do not have capacity to see PwHD as often as needed due to lack of access to facilities, HCPs and referral networks. From the literature it has been established that HD teams require a key worker who co-ordinates care and manages the complex referral process within the service, acting as a single point of access for service users. Some evidence suggests that HD specialist nurses are best placed to take on this responsibility [22]. In addition, an evaluation of an HD service in the UK found that the role of a specialist nurse as a care coordinator was an essential element for the functioning of the team and delivery of quality care [23]. Wilson and colleagues [24] also highlight the importance of a key worker in HD who can improve access for PwHD attempting to navigate different supportive services and HCPs appointments. In any case, this research supports the idea that an individual who manages multiple services for PwHD is important for providing the best care and avoiding the referrals loop highlighted by HD specialist services in this study.

The authors also note that other neurodegenerative diseases such as Parkinson's disease have had clinical specialist nurses (who acted as care coordinators) in place for many years [24]. Indeed, some HD services in the UK do have this role. In Scotland, the Scottish Government backed National Care Framework for HD specifies that "care co-ordination should be provided by a single named specialist." HD specialists (individuals who co-ordinate HD care) employed by the SHA and funded by NHS Boards and Health and Social Care Partnerships are found in 8 of 10 HD services in Scotland (see Table 2). However, many services in England and Wales do not have such an individual and there is no policy or mandate for this role in the context of HD throughout the whole of the UK.

The formal integration of HD services, particularly at the national level, can enhance access to specialized care, optimize resource allocation, and facilitate a more efficient service delivery. However, this process is also linked to potential challenges, including the need for thorough planning, addressing administrative complexities, and ensuring effective communication [25]. Further research is necessary to support and enhance the integration process.

Conclusions

To our knowledge, this study is the first to undertake a comprehensive review of specialist services for HD in the UK and to provide insights into the number and location of HD specialist services as well as the PwHD population served by these services.

This research highlights the variation in organization and capacity within individual HD specialist services as well as current resourcing and gaps in access that influence this capacity. Gaps in access were driven by lack of resources (e.g., availability of facilities or HCPs) however, this study identifies challenges with willingness of HCPs and PwHD in the UK which mean that even when HCPs are available, PwHD do not have access to required services. This is particularly evident in the provision of mental health services for PwHD.

This study was designed to provide an overview of specialist centers in the UK. Further research should be done examine the organization of HD services and how resources are utilized to understand the differences and explore the impact of service organization on care quality.

Consensus guidelines for the management of HD both internally in the HD services and externally for referrals to wider services are urgently needed to improve access. One recommendation is that care coordinators would be beneficial to access HCPs and navigate a complex and time-consuming referral processes. The absence of an HD-specific service agreement for the way services are commissioned is a significant challenge.

The data derived from this study provide evidence for the HD community that can be used to support future resource needs of HD specialist services. It is an important time to consolidate HD services across the UK, as once novel therapies become available, there may be increased demands on these services; thus, future planning is essential.

Limitations

While every effort was made to collect a representative sample and coverage of services, three centers in England and one in Northern Ireland did not participate in the quantitative phase. This can be considered as a limitation as the results do not adequately cover the UK in its entirety. Some questions in the quantitative phase may have been subject to recollection bias as they were asked questions relating to the previous

12 months, although these questions were kept to a minimum.

Interviews can be more easily influenced by the personal biases of the interviewers or interviewees as they may have had their own opinions on certain topics, which may have led to biased probing or closed questioning. Although virtual interviews had advantages, such as accessibility, there were some limitations such as being largely restricted to verbal responses, researchers could not respond to non-verbal cues, and it may have been difficult to build sufficient rapport. However, this is not considered a large limitation for the study as the majority of interviewees were conducted via video call in order to minimize this limitation.

Finally, this study is the perspective of the HD specialist center. The respondents were primarily clinicians or nurses that are involved in running the HD specialist center. It should be considered that the perspective of the patient is not discussed here.

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CONFLICT OF INTEREST

Wendy Kane and Rachel Blair are employed by Roche Products Ltd. Hugh Rickards, Anne Rosser, Alistair Haw, Cath Stanley received a consultation fee from Roche Products Ltd. for this work. Idaira Rodriguez Santana and Pushpa Hossain are employed

by HCD Economics and Rosa Willock and Maria Doherty were paid employees of HCD Economics while this research was conducted.

DATA AVAILABILITY

The quantitative data supporting the findings of this study maybe be available upon reasonable request from the corresponding author. The data are not publicly available due to privacy, ethical restrictions, or other concerns.

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