Are people experiencing person-centered integrated care? The answer by people living with Huntington's Disease

In 2023, we did a survey to capture the experiences of people living with Huntington's Disease (HD) in England. The survey was designed with the support of people who had lived experience of HD. We wanted to find out:

- If people's health and care needs are well met
- If care is joined-up and coordinated, from the perspective of people using services

"There doesn't seem to be any joined up thinking or best practice (...)

It is up to me to initiate anything we need"

- Integrate-HD survey participant

Key findings

Integrate-HD is the largest published survey involving people living with Huntington's Disease in England. 153 participants took part, including people at risk, diagnosed, carers and former carers.

The survey shows that:

- People have serious unmet complex needs, particularly regarding mental health and social care.
- Carers feel ignored and not cared for.
- People report fragmented care.
- There are geographical inequalities (post-code lottery) in health and care access.

This document is a lay report of the Integrate-HD survey study.

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Full report with free access

The results of the Integrate-HD survey were published free access on the 8th October 2024 in the Journal of Huntington's Disease. You can access the full scientific article by clicking here: https://journals.sagepub.com/doi/abs/10.1177/18796397241288449

Acknowledgements

We are very grateful to the patients, relatives and the public who contributed to this work, particularly to the Huntington's Disease community support and engagement.

Let's look in more detail

Person-centered care

In our study, we used this definition of person-centered coordinated care:

"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me". National Voices (2013)

We asked people to rank how much their care experience matched this description. From all the groups, carers rated their experience the lowest, with an average score of 4 out of 10 (10 being the best experience).

Most participants (65%) gave a neutral or low score, indicating that their care is not person-centered.

Expert knowledge

The professionals more frequently mentioned as being involved in Huntington's Disease care were: general practitioners (GPs), neurologists, social workers and HD charities.

We asked participants if they found these professionals to be knowledgeable about HD.

Although GPs and social workers were very involved in HD care, people did not consider them to be knowledgeable about the disease. In the other hand, neurologists and HD charities showed a good balance between involvement in care and HD knowledge.

Coordination

Although 90% of people said it was very important to have a professional coordinating their care, only 19% said to have access to such a professional. Care coordinators were identified in only 40% of the English counties.

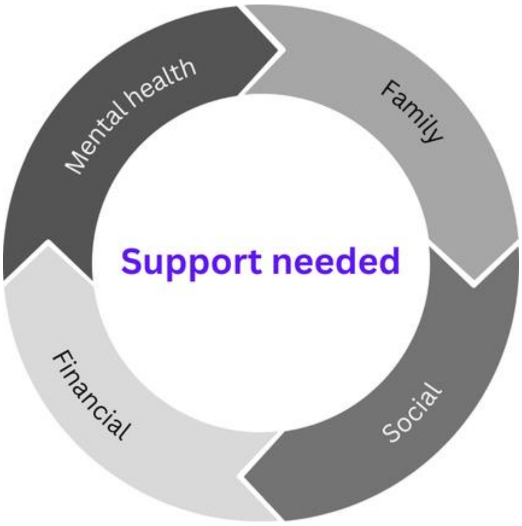
Nearly half the care coordinators identified, worked as nurse specialists. People with access to a care coordinator reported a much better care experience.

Continuity

Although people felt it was important to see the same professional at every appointment, rarely this happened. Particularly in the case of GPs, most people said to never see the same GP. Continuity improved in the case of neurologists.

The change and variety in health and care professionals caused duplication of information. Nearly 60% of people said they needed to repeat information to different professionals most of the time or always.

Most important care needs



People asked for improvements in several areas			
Carer's support	Family-focused approach	Suitable care settings	Improved access to care
Expert knowledge and continuity	Single point of contact	Coordination between professionals	Public awareness
And more: GPs training, legal and practical support, research access, etc.			

So what?

Our research has implications for practice, policy and research in Huntington's Disease.

- **A care coordinator can help navigate the "HD care web" and improve people's care experiences.**
- **Carers need formal recognition as part of the care workforce, with financial remuneration.**
- **Further research should test the impact of a HD care coordinator, to understand their benefit and costs.**
- **An intervention that improves care for the HD community is likely to have different strategies. The success of the intervention needs to be assessed from people's perspectives.**

Integrate-HD provides important findings, showing the current standard of HD care in England. This allows us to track progress and set the direction for future action.

What have you done with this information?

Publishing the results of the study and reflecting on its implications is very important. We were very pleased that the study was published open access in the Journal of Huntington's Disease, a credible and valued scientific journal.

Unfortunately, we do not believe many people have the time or the will to read papers. Sandra has been taking the findings to different settings, speaking to clinicians, leaders, academics and researchers in the field of neurology and rare diseases. We also presented the findings to the Huntington's Disease Association England & Wales, which have included the evidence in their latest mental health report, calling for government action. You can read the report here: Huntington's Disease Association - Unseen and Unheard - Mental Health in Huntington's disease (2024).

Sandra has presented this research in varied type of events, in England, Northern Ireland, The Netherlands, Italy, France and Portugal. She is part of national, European and international groups, continuously advocating for better integrated care in the field of Huntington's Disease and challenging care providers to provide more person and family-centered care.

What now?

We would like to sincerely thank you for taking part in the Integrate-HD survey. This was the second phase of the project.

Sandra has continued to gather evidence in how to provide better care for people living with HD. She has completed interviews with service users and service providers. She has ran consensus workshops to get agreement on what matters to people and how to improve care for the HD community.

Now, Sandra will analyze all this information, and next year she will present what an integrated care model needs to look like, to meet the complex needs of people living with Huntington's Disease, and how to measure this change at a person's level.

You are very welcome to contact Sandra with questions, comments or feedback using any social media platform, or email her at smbp1u20@soton.ac.uk.

Sincere thank you and sending you all strength,

Sandra

Sandra Bartolomeu Pires

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