



HD Voice 'Expert by Experience' Information Sheet

HD Voice is our Expert by Experience group, empowering people affected by Huntington's disease to influence research and the internal work of the Huntington's Disease Association.

HD Voice volunteers make a real difference; shaping research and resources through their lived experience.

WHAT DOES IT INVOLVE?

Research support:

Assisting researchers with tasks such as:

- Commenting on proposed research plans
- Joining focus groups
- Reviewing patient information sheets
- Reviewing guidelines for professionals
- Becoming ongoing 'patient' representatives on research projects
- Contributing to our Quality Assured panel for care-home accreditation

Important Clarification – Supporting Research, Not Participating

HD Voice volunteers bring their lived experience to **support** research—reviewing documents, advising on design, and joining focus groups. **They do not participate as research subjects** in clinical trials or studies through HD Voice.

If you're interested in **participating** in research trials or studies, please visit our research pages.

Huntington's Disease Association internal projects:

Support the Huntington's Disease Association by:

- Reviewing website updates or literature
- Helping plan and develop Huntington's Disease Association projects

The goal of HD Voice is to ensure that research and resources are relevant to the needs of people affected by Huntington's disease.



WHO CAN VOLUNTEER THROUGH HD VOICE?

Anyone with a personal connection to Huntington's disease, including:

- People displaying Huntington's disease symptoms
- People who have the gene for Huntington's disease but are not symptomatic
- People at risk of Huntington's
- Current or former carers
- People who have tested negative for Huntington's disease

HD Voice volunteers should feel comfortable sharing their experiences engaging with researchers, Huntington's Disease Association staff and the community.

COMMITMENT

How often? Around once a month, depending on demand

Response deadlines? Typically 2 weeks, but vary by task

How might I get involved?

- Focus groups (Zoom/Teams)
- 1:1 phone calls
- Written feedback by email
- Ad-hoc requests for comments / discussions etc

Tracking your impact. We ask volunteers to let us know about their involvement as it helps us measure the impact of HD Voice.

Participation is optional. We ask that you respond wherever a request is relevant to your experience / circumstances - more responses gives a wider perspective.

TRAINING AND RECOGNITION

Training: Not formal training, but we welcome suggestions

Honorarium: Volunteering is unpaid, occasionally small payments may be offered by researchers.

Expenses: Almost all HD Voice opportunities are virtual and not expected to incur expenses. Please do speak to us if you are likely to incur expenses.

LEAVING HD VOICE

You can withdraw at any time – just let us know and we'll update our records.



**Huntington's
Disease
Association**

DATA AND PRIVACY

Your data is stored under our privacy policy www.hda.org.uk/privacy-policy/.

Please contact us if you have any questions or concerns.

HOW TO JOIN

If you are interesting in volunteering with HD Voice, please fill in the application form on the websites, or contact us using the contact details below:

[Apply here to volunteer](#)

If you have any questions about Volunteering please feel free to get in touch via:

- Email: volunteer@hda.org.uk
- Telephone: 0121 647 8263
- WhatsApp/Text: 07749 493 677



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