



**Huntington's  
Disease  
Association**



## **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.



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## DATA AND PRIVACY

Your data is stored under our privacy policy [www.hda.org.uk/privacy-policy/](http://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](mailto:volunteer@hda.org.uk)
- Telephone: 0121 647 8263
- WhatsApp/Text: 07749 493 677



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