

HD Voice Information Sheet



Huntington's
Disease
Association

HD Voice is an initiative by the Huntington's Disease Association which gives families a voice in Huntington's disease research and the internal work of the Huntington's Disease Association.

What does it involve?

Research: Assisting the Huntington's Disease Association with requests from researchers across a variety of tasks such as commenting on a proposed piece of research, attending a focus group or reviewing patient information sheets. Occasionally there are requests for volunteers to become longer term 'patient' representatives on research projects. In general HD Voice is about supporting research not being a participant in the research, however we do also circulate relevant surveys etc. so members of HD Voice can respond as they see fit.

Internal work: Assisting the Huntington's Disease Association with internal work such as updates to web-pages / literature and having a role in the planning and development of Huntington's Disease Association projects.

We believe that HD Voice enables, research and resources to be more relevant to the needs and concerns of the people that matter most.

Who can become a member of HD Voice?

- Those who have experience of Huntington's disease as someone with Huntington's / Carer (including bereaved carers)/ Person at risk or who has tested negative.
- Those who have confidence in working with a mixed group of patients, carers, health professionals, researchers and Huntington's Disease Association staff.
- Willing to share their experiences within the group.

How often will I be asked to get involved?

We have little control over the requests that we receive, but currently requests are average about one a month.

How long will I have to respond?

Each request will have its own timescale, we aim to give around two weeks for feedback but this will depend on the request.

How will I input?

We will usually invite you to a zoom call to discuss a topic or send information by email.

Will I have to respond to all the requests that are sent out?

We ask that you respond wherever a request is relevant to your experience / circumstances The more responses we have gives the widest perspective.

How do I give feedback?

This will depend on the project, it may be within a zoom call, we may ask you to fill in an on-line survey (using survey monkey) or we may ask you to email responses.

If you respond directly to a researcher, we ask that you let us know about your involvement (with an approximation of time spent) so we can track the output of the group. If you are involved in an on-going project (perhaps on a steering committee) we ask that you let us know about meetings you are attending / work that you are inputting, with an approximation of time spent (either each time you have involvement or drop an email on a monthly basis).

Will I receive training?

We are planning to trial the use of training webinars for the group.

Will I get paid?

Members of HD Voice are volunteers. You will be reimbursed for travel costs associated with HD Voice, where this has been pre-agreed. Where external researchers are asking for HD Voice to support their research they will be expected to cover expenses.

What if I decide I don't want to be involved anymore?

If you join but later decide you don't want to take part please let us know as soon as possible.

How do I join HD Voice?

Please contact HD Voice for an application form or an informal discussion.



0151 331 5444



hdvoice@hda.org.uk

Contact us

Huntington's Disease Association
Suite 24, Liverpool Science Park
ICI, 131 Mount Pleasant
Liverpool, L3 5TF

Phone: 0151 331 5444
Email: info@hda.org.uk
Website: www.hda.org.uk

Registered charity No. 296453
Company No. 2021975.