



HD Voice – Information for researchers

HD Voice was established in 2017 with the aim of giving people with experience of Huntington's Disease a voice in a variety of projects. We have around 30 members at present who have a range of experience with Huntington's disease (people with symptoms, people who are at-risk, are carers, or have had a negative test), All of these people volunteer their time to be part of HD Voice.

What is HD Voice?

HD Voice is a panel of volunteers who help researchers learn about the needs of families living with Huntington's. They work on different projects to help researchers plan and develop their ideas.

We believe that by encouraging involvement from people with direct experience of Huntington's, research will be more relevant to the needs of the people who need it.

How can we support researchers?

HD Voice can coordinate opportunities for people affected by Huntington's disease to be involved in your work. We will ask you for information about your project, study or trial and discuss with you how we can support you through HD Voice.

We do this through:

- Request members to attend a zoom call(s) (facilitated by the researcher)
- Request members to complete a survey (created by the researcher)
- Request members to respond to an email request to the researcher
- On-going support as the patient voice on steering groups etc.

Members of HD Voice decide if they feel that it is a project they can be part of. We can't guarantee that we will be able to support every project.

Following a discussion with HD Voice, we ask that you draft an email which, once approved, can be emailed out to the group.

We ask that you include:

- A paragraph about the study in laypersons terms
- Who you need to be involved (e.g. anyone affected by Huntington's disease, or a sub-group)
- How they get involved, and what the time commitment is (e.g. 'a 5 minute survey' 'an hour zoom call' 'an on-going monthly commitment')
- If there is a limit to the number of people you want to be involved, and if so how they will be selected (e.g. Is it a 'first come, first served' basis?)
- Any guidance needed in terms of confidentiality (and if any paperwork that might be sent out needs to be destroyed)
- Who to reply to

We would ask that you:

- Report back to HD Voice who has been involved (for our internal monitoring)
- Provide feedback on the support received and the impact on your research (by sending an email to HD Voice)
- Provide feedback on the study outcomes, in lay persons teams once the research is completed

Payment:

At the current time we do not ask for any payment. This may be reviewed in the future. We would expect you to cover any volunteer expenses if there was a cost involved to the participant and we would ask that you make this clear to the participant before they agree to being involved.

To request our support, or for further information please contact: hdvoice@hda.org.uk

Contact us

Huntington's Disease Association
Suite 24, Liverpool Science Park
IC1, 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.