

Barriers to participation in research and how to overcome them

Summary of main comments from an anonymous focus group held at the Huntington's Disease Association Annual Conference, Oct 2007, run by Terry McGrath from DeNDRoN. The group of seven included patients, gene-positive asymptomatic carriers and carers. This initial report is being sent to HDA and DeNDRoN's HD Clinical Studies Group.

Finding out about research opportunities

- At regular HD appointments, doctors sometimes don't seem to mention research opportunities unless asked. When they do, they don't make it explicit whether it's for information, or whether they are specifically inviting the patient to participate.
- Patients reported frustration about receiving letters about particular pieces of research, replying with an expression of interest, but then hearing nothing further.
- Sometimes not clear exactly how different research teams, from whom they receive letters, 'fit in' with each other, and with HD Registry.

Suggestions

- Be explicit in consultations when inviting patients to consider participation.
- Clear, short information sheets.
- If researchers write to patients about a specific study, researchers should then always follow-up on patients who reply expressing interest. The team should explain how they know of the patient, and how they 'fit in' with the HD Registry and patient's doctor.

Practicalities around appointments

- Long distances to research appointments.
- Only one or two people seem able to do the assessments.
- Reimbursement can take a long time.

Suggestions

- Faster travel reimbursement system.
- Travel expenses kitty.
- Maybe research appointments somewhere close to where the patients live.
- Avoid extra visits by training staff locally to do research assessments, following an objective system, without needing senior staff to help.

Confidentiality

- Major concern of asymptomatic HD gene-positive people, if their families and employers are unaware of their status, is how to explain any time away visiting researchers.

Suggestions

- Researchers to think through the difficulties that this can mean for some asymptomatic HD gene-positive people considering research.
- Keep to a minimum the number of appointments.
- Flexibility around appointment times – maybe Saturday appointments
- Close to where person lives or works.

Managing possibilities for ‘bad news’

- Lack of clarity about what all the possible types of ‘bad news’ from tests might be.
- Concern re risk of finding out something you definitely did not want to know.

Suggestions

- Clear guidance on the potential for ‘bad news’ which the tests being done might reveal, and what would happen with the news.
- Clear guidance whether patients can be in a study whilst stipulating that they do not want to know the results.

Research work with quite ill people

- Remembering to keep to medicine regimes, and other procedures.
- Particularly difficult if coping without a carer.
- It was felt by some that Lasting Power of Attorney could be a way to give patients with advanced HD more opportunities for research participation. This could be relevant in neuro-transplantation research.

Suggestions

- Research designs should take into account those coping without a carer and allow for memory problems.
- Clarity about the impact of Lasting Power of Attorney for HD research could be useful.

Some additional comments

Several participants said they’d heard a lot about how effective “the placebo effect” seemed to be in HD (e.g. treatments for depression) and suggested that research into it might be useful.

The fact that DeNDRoN includes research across dementias and other neurodegenerative diseases was welcomed as expanding the chances of outcomes of relevance to HD.