

PPI in specific DeNDRoN-supported studies

SUMMARY OF THIS PAPER

- It looks at DeNDRoN PPI in three specific studies (one PD, one HD, MND {ALS}, and one AS).
- This is a chance for the PPI Working Group to comment on the role of PPI with three specific studies. Rather than the detail of the studies, the aim is to discuss the PPI aspects.
- We can consider how useful we feel that the various methods of involvement are, e.g. local discussion groups, reference panels.

MUSTARDD-PD - Multicentre UK study of the acetylcholinesterase inhibitor donepezil in early dementia associated with Parkinson's disease

OVERVIEW: The objective of this randomised controlled study is to evaluate the clinical and cost-effectiveness of the cholinesterase inhibitor donepezil in the long term management of people with relatively mild dementia associated with Parkinson's disease. The outcomes of this study will inform prescribing policy for the use of these agents in this indication. They will also make a significant contribution to removing uncertainty regarding clinical effectiveness, and reduce variability in the use of "anti-dementia" drugs in this context. The total study duration is 60 months.

Full details at: <http://www.hta.ac.uk/project/1967.asp>

Suggested DeNDRoN PPI activity

1. It is envisaged that DeNDRoN LRNs may send the draft Patient and Carer Information Sheets (once drafted) to individual pt/carers contacts for comment. Terry McGrath to circulate these to LRNs, when available.
2. There are already two lay members on the Study steering committee. It is envisaged that they will help to identify MUSTARDD-PD study issues which one or two LRN focus groups might explore in more depth. A particular issue mooted already is how to broach issues around dementia in PD with patients, with respect to the study.

RESULT - Review of Epidemiology and Service Use in Rare Long Term neurological conditions

OVERVIEW: The RESULT study is looking at service provision for people with rare long-term neurological conditions, to inform the implementation of the National Service Framework for Long-Term Neurological Conditions. Specifically, the study will be focussing on people with motor neurone disease (ALS), Huntington's disease, multiple system atrophy, dominantly inherited ataxias, progressive supranuclear palsy, post polio syndrome, and charcot marie tooth disease. This study aims to investigate the current provisions of care and treatment and how they need to change. It will, among many other aims, provide detail of care management such as the timing of referral, drug history, access to rehabilitation and palliative services. This information will be available by population group, enabling breakdown by age, sex, ethnicity and locality.

Full details at: http://www.ltn.org.uk/research_files/RESULT_study.html

Suggested DeNDRoN PPI activity

1. DeNDRoN is helping with identifying people for a national Patient/Carer Reference Panel of patients and carers to review and advise on aspects of the study. The panel will exist as a

‘virtual’ group and not all members will necessarily meet face-to-face. One issue is whether ‘representatives’ from smaller organisations might be on the panel, as well as patients and carers themselves.

2. DeNDRoN has offered the use of the Portal, if appropriate, for ‘virtual’ meetings, but another possibility is smaller localised face-to-face meetings.

DOMINO-AD - Donepezil and Memantine in Moderate to Severe Alzheimer’s disease

OVERVIEW: Alzheimer’s Society and the Medical Research Council are supporting a large clinical trial currently recruiting at centres around the UK. The DOMINO trial will investigate whether an extra 12 months of treatment with donepezil or memantine – or a combination of the two drugs – has benefits in terms of cognition, quality of life and delay a move into care. The aim is to recruit 850 people with Alzheimer’s who have been taking donepezil but have reached the point where NICE guidance would mean they would have to stop treatment. As the trial is not funded by the pharmaceutical industry, the results will be seen as independent and therefore much more influential with policy makers. Trials are taking place in Belfast, Birmingham, Cambridge, Dundee, Glasgow, Leicester, London, Manchester, Newcastle, Nottingham, Oxford, Southampton and Warwick.

Full details at: www.iop.kcl.ac.uk/domino

Completed DeNDRoN PPI activity – to discuss whether this was useful

Two focus groups were carried last year (in Bath and Thetford) which largely or solely looked at DOMINO-AD. Points emerging were fed into Local Research Networks and to the Dementia CSG. Here, for background, is a summary of points from the discussions:

Stopping donepezil to join the DOMINO study

- Stopping donepezil to join the study, at a particularly difficult stage of the illness, was a potential concern. If a patient on donepezil were in “a manageable situation”, carers said that they would be wary of risking inviting “unnecessary disruptions”.
- Even with an option to go back onto the pre-study dose of donepezil if a patient began to decline on the study drug, carers said they had concerns about a potentially drawn-out recovery period.
- As some clinicians follow these NICE guidelines more firmly than others, one query was whether DeNDRoN’s focal point for recruiting more patients might be to concentrate on the clinicians who are firmly following the NICE guidelines.

Explaining the study

- More time explaining the study could help. It was felt that doctors and nurses should be especially encouraging about DOMINO providing a 3 in 4 chance of remaining on an active medication.
- Specialist Nurses were felt to be key to explaining the study.

Carer fatigue

- Fatigue and time pressures among carers may be recruitment and retention issues. It was suggested to add new elements to the DOMINO research visits aimed specifically at ensuring they are a positive social experience for carers.

Other suggestions from carers

- Make GP referrals to the study easier.
- Keep up efforts to go directly to patient groups to increase local awareness.