

PPI perspectives on how to link national Clinical Studies Groups and Local Research Networks

SUMMARY OF THIS PAPER

DeNDRoN's local and national activities should relate more closely. Reviewing lay members' ideas reproduced below can help us look at:

- bringing together study development, with study delivery
- bringing together decisions nationally on study adoption, with LRN decisions on the achievability of those studies
- how to relate LRN challenges (including PPI concerns), with national issues

Background

It is recognised that DeNDRoN's local and national activities should relate more closely. Twenty lay members of DeNDRoN's national Clinical Studies Group (CSGs) took centre-stage at a multi-disciplinary gathering in March, along with other experienced lay members from DeNDRoN LRN Steering Committees, and Local Research Network (LRN) staff, and chaired by Doug Mitchell and Steve Illiffe. A crucial aspect of the discussion was input from six clinicians/researchers from across the CSGs.

Key recommendations relevant to the link between LRNs and CSGs were:

- There was a very clear demand for action as soon as possible for more co-ordinated work across the CSGs.
- One of the top concerns expressed was that DeNDRoN should increase efforts across all our CSGs to develop outcome measures more relevant to patients.
- There was a call for projects (maybe even in the form of research studies) around identifying patients' & carers' research priorities, along the lines of the PD CSG activity on this, initiated by a lay member of that CSG.
- There needs to be faster work around databases of patients who are interested in future research opportunities. It was felt that these could help DeNDRoN work to overcome regulatory delays in getting studies set up at LRN level.
- An imaginative effort was called for to increase the opportunities for PPI at the design stage.
- CSGs and LRNs need to pay proper attention to all the various dementias and neurodegenerative diseases, not just a sub-set. Participants recommended that now that CSGs are suitably established, they should widen their horizons beyond the most common disorders.
- Patients and carers also recommended much more conjoining of the CSGs with the Local Research Networks' work-streams in DeNDRoN.
- There was a general sense that lay members need to be invited to become more fully a part of the everyday work-streams within LRNs and in DeNDRoN CSGs.

There was a positive sense that the day was a good example of what can be achieved by combining staff, academics and lay members as equal partners. Lay members on the Dementias CSG and in the MND CSG reported positively on their constructive pieces of work around producing research information databases, in conjunction with medical charities. Lay members left saying they were willing to work towards this joined-up approach within their individual committees, pushing for an holistic DeNDRoN outlook.