
DeNDRoN update

July/August 2007

Coordinating Centre news

Delivering, and developing, clinical research for patient benefit: 2007 Conference key messages

DeNDRoN's inaugural conference highlighted the central role that the network will play in the establishment of an infrastructure delivering quality research across the neurodegenerative diseases, and noted the substantial progress made so far by the network in achieving these aims

- DeNDRoN is succeeding in engaging people from across geographical and specialty boundaries (neurology, old age psychiatry, gerontology and general practice)
- DeNDRoN has established seven Clinical Studies Groups (CSGs) that bring together more than 100 leading academics. All DeNDRoN CSGs are beginning to develop new research proposals. The conference poster display of 33 posters pointed to considerable research activity in relevant areas
- DeNDRoN is linking with networks across the devolved nations and, through the CRN, across all of England. DeNDRoN will be working closely with the CLRN to obtain support for DeNDRoN studies outwith the LRNs
- The government is fully behind DeNDRoN: Lord Hunt OBE, Minister of State for Quality, and Harry Cayton OBE, National Director for Patients and the Public, DH, both made positive addresses to conference delegates
- Patient engagement in DeNDRoN is vital, and there is already a strong engagement of patients and patient organisations showing the commitment to work with the network
- There is an urgent need to develop better, and more appropriate, outcome measures for research in our field, and an urgent need to establish what outcomes are important to patients at different stages of their illness. DeNDRoN's Special Interest Group in Research Methodology is amongst the first in the UK to work in this area
- All the major funders of brain tissue banking have come together to develop a national strategy with the aim of making the UK a world leader in brain banking. DeNDRoN has convened a CSG for neuropathology & brainbanking that will tie in closely with this initiative, and hopefully become a key partner within this strategy group
- We are at a very exciting moment in respect of primary care research in dementia. The inclusion of dementia in the Quality and Outcomes Framework (QOF), which looks at diagnosis and management, provides an excellent opportunity for enabling primary care to support and deliver research in dementia
- A new system for funding NHS Support for research is beginning to be established across the UK. Leading experts in their fields are developing a transparent system through which dedicated support from appropriate skilled staff will be provided as needed to support research activity
- This is an important opportunity to create a new system for supporting research in these diseases, and DeNDRoN has shown that it has a central role to play in this development

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Personnel and recruitment

Jenny Baverstock has left the South Coast network. We wish her luck with her new job and thank her for all the hard work she has put in getting the network established. Jenny is moving back into primary care research, working for one of the new PCRN. The South Coast network is investing some of their resource in the PCRN, so Jenny will not be able to escape DeNDRoN!

The advert for Jenny's replacement will be going out shortly, with interviews held in September. If you know anyone who might be interested in this job (based in Southampton) please do ask them to contact me or David Wilkinson.

NIHR developments

The NIHR website (<http://www.nihr.ac.uk>) now features the latest information relating to NIHR faculty, including the latest implementation plans. New developments relating to research passports will be added soon, so it's worth checking the site regularly for news and policy updates.

Thames Valley DeNDRoN conference

DeNDRoN Thames Valley (Oxfordshire, Buckinghamshire, Berkshire and Northamptonshire) will host its Inaugural Dementia Research conference and networking event at the Unipart Centre, Oxford on Wednesday 12 September 2007.

The theme is: 'Quality service and Quality research: a two-way relationship'. We will explore the ways that research activity can enhance the clinical service patients receive and the means by which clinical services can promote research activity.

The conference aims to:


- Provide practical information about how we should respond to recent developments in law, clinical practice, and research.

- Provide a forum to share experience with colleagues working across Oxfordshire, Buckinghamshire, Berkshire and Northamptonshire
- Highlight some of the important clinical research that is being conducted in the Thames Valley
- Deliver an innovative workshop during which patients and carers will help to train NHS staff on how best to approach the topic of research.

During the workshop, patients or carers will work with small groups of healthcare professionals describing and exploring how it feels to be asked about research from a patient or carer perspective. Essentially, we want our patients to become our teachers. For more information please contact: Olivier Bazin, DEEPARC Administrator, email: obazin@dendron.org.uk To book a place at the conference please contact Paula Lloyd-Chamberlain, email: paula.lloyd@ngh.nhs.uk, tel 01604 545941.

South West DeNDRoN launch meeting

SW DeNDRoN will be holding two launch meetings, one for each hub, on the 10 and 12 September. The agenda includes an explanation of DeNDRoN and its aims, an over view of the structure, a review of current and developing treatments, plus views from consumers. There will also be a Q+A session and an exhibition.
Bristol: Monday 10 September, BAWA, 589 Southmead Road, Filton, Bristol, BS34 7RG. From 13.30-17.00
Plymouth: Wednesday 12 September, Future Inn Hotel, International Business Park, Plymouth, PL6 5ZD. From 13.30-17.00

The full agenda and registration details are available on the DeNDRoN website under the 'forthcoming meetings' link. 

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North Thames DeNDRoN study afternoon

North Thames DeNDRoN is holding a free study afternoon on dementia research in primary care on Wednesday 12 September 2007, from 12:45 – 16.30 at SOAS, London. This event is an exciting opportunity to hear from experts in the field of primary care dementia research, practice and policy, and is open to all professionals and researchers working in primary care dementia research. The event will include an introduction to the North Thames DeNDRoN Local research network and key issues in dementia research in primary care, plus presentations of dementia research in progress.

The event will take place in the Lecture Theatre V111 (first floor), School of Oriental and African Studies, Vernon Square Campus, Percy Circus, London WC1X 9ET, off King's Cross Road. Nearest tubes: King's Cross, St Pancras and Euston. The full agenda and registration details are available on the DeNDRoN website under the 'forthcoming meetings' link.

PPI focus

DeNDRoN priority areas for PPI

An assessment of the potential added value which PPI can bring to each of DeNDRoN's processes has helped to identify priority areas. This follows discussions started in March with patient representatives and medical charities, and has highlighted priorities in terms of the likely potential for PPI to add value. These are:

- strategic management locally and nationally
- overall clinical strategy and any gaps
- the working up of specific proposals
- the feasibility assessment process
- enhancing patient recruitment to studies
- and the interpretation of results

The main recommended models for PPI are likely to be formal representatives on committees and working with medical charities and patient

representative bodies, combined with a supportive role for Patient/Carer Advisory Panels, formed either locally or nationally as a permanent reference group set up to monitor and advise on a specific activity. These proposed priorities will be circulated initially to the Road Map Group members, as part of the group's expansion into an ongoing PPI Working Group.

Communications

DeNDRoN annual report

It is expected that this will be published for circulation during August. Any news, snippets or information from around the network are most welcome for the editorial 'showcase' section.

NIHR identity

Following the first NIHR identity workshop, all the topic networks will now begin to adopt the first phase of the NIHR identity programme. As a pilot for this project, DeNDRoN communication materials are already using the NIHR logo as requested by NIHR, and other research networks will now begin to follow suit.

The new phase of the implementation plan will also see the introduction of a series of 'relationship' and 'funding' statements to be used as appropriate on communications materials. Advice and guidance on usage will be available from Coordinating Centre. There are several issues to be finalised with regard to the NIHR identity and its usage by topic networks, mostly relating to the situation regarding the devolved nations and the UKCRN. The Coordinating Centre will be seeking your views on these matters in the coming weeks.

The deadline for information for the next DeNDRoN Update is 10 September.

Relevant items will be submitted to the next issue of the UKCRN News for the Networks.

Please send submissions by emailing: newsletter@dendron.org.uk