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**Minutes of DeNDRoN PPI Working Group  
29<sup>th</sup> July 2009**

Held at DeNDRoN Coordinating Centre, Mecklenburgh Square, London (020) 7905 2995

PRESENT

**Dr. Steve Iliffe** - Chairperson, DeNDRoN Associate Director who has the PPI portfolio on the Executive  
**Professor Geoff Hanks** - Patient Representative  
**U Hla Htay** - Patient Representative  
**Dr. Jean Waters** - Patient Representative  
**Peter Webb** - Patient Representative  
**Dr. Belinda Cupid** - Research Manager, Motor Neurone Disease Association  
**Bunia Gorelick** - Research Grants Manager, Parkinson's Disease Society  
**Dr. Susanne Sorensen** - Head of Research, Alzheimer's Society  
**Olivier Bazin** - from Thames Valley DeNDRoN  
**Lisa Curry** - from North Thames DeNDRoN  
**Clare Jones** - from North West DeNDRoN  
**Jenny Keylock** - from DeNDRoN Supplementary Resources  
**Yvette Lycett** - from South Coast DeNDRoN  
**Dr. Margaret Piggott** - from North East DeNDRoN  
**Juniper West** - from East Anglia DeNDRoN  
**Maryrose Tarpey** - Public Involvement Adviser, INVOLVE  
**Piers Kotting** - (*from 1.00pm*) Assistant Director, DeNDRoN  
**Terry McGrath** - PPI Co-ordinator, DeNDRoN

APOLOGIES

**Professor Douglas Mitchell** - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN  
**Dr. Helen Santini** - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association  
**Deborah Howcroft** - from South West DeNDRoN  
**Roger Steel** - PPI Manager, NIHR CRN  
**Dr. Marianne Miles** - PPI Lead, NIHR CRN  
\*\*\**Ex officio*: **Professor Martin Rossor** - Director, DeNDRoN

## **MINUTES of the DeNDRoN PPI Working Group held on 29th July 2009**

### **1 Introductions and welcomes**

Peter Webb was welcomed as the new member of the Group.

### **2 Minutes from last PPI Working Group (9/3/09) and matters arising**

Minutes were accepted.

#### **2.1 External Review**

Now that DeNDRoN has successfully come through the DH review process, the PPI Working Group is interested to know the detailed plans.

Steve Iliffe said that DeNDRoN's proposed plans – covering all aspects of DeNDRoN for five years to 2015 – will be much clearer by the end of August.

Probably among these overall plans will be improvements to:

- increase third sector involvement systematically, and also
- develop broader study recruitment methods with a vision which includes, for example, social care and care homes.

The PPI Working Group asked whether there will be a consultation about the overall plan for the five year plan – including patients/carers, medical charities, the Association of the British Pharmaceutical Industry (ABPI), etc – as it does need PPI input, above all about the PPI aspects.

Steve confirmed that DeNDRoN will seek active involvement as the plans develop. The next PPI Working Group meeting will focus on this.

NIHR CRN could send DeNDRoN some examples of PPI in strategic development if wished.

#### **2.2 Survey**

DeNDRoN South West will run the pilot of the survey as discussed previously. Terry commented again that this is just a snapshot of the degree of PPI in relevant research, plus a chance to gather some personal comments from researchers on PPI. Probably ready mid-October. Terry McGrath to send to Jean Waters too, for info.

Steve Iliffe says we'll await results with interest, but was clear that DeNDRoN Executive think PPI is a sine qua non in any case.

#### **2.3 Obtaining feedback from research participants**

The North Thames DeNDRoN ideas will be discussed by DeNDRoN Executive shortly.

#### 2.4 Offering payment for 'time'/'attendance' to CSG lay members

Terry McGrath commented that this seems to be going well; suggesting it's better described as payment for expense around attendance than payment for time. Terry also added that 100% of lay members on national DeNDRoN committees were appointed before payment was planned.

Lisa Curry - and others - highlighted the inexplicable inconsistency with LRNs, which cannot similarly pay people. Clarification was requested as to why the difference exists.

### 3 **Paper A - PPI in specific DeNDRoN-supported studies**

Appendix Paper A (previously circulated) has study details.

#### 3.1 Mustardd-PD study

Terry briefly outlined the study. His approach for Mustardd-PD PPI include...

- 1) Two lay people on Steering Group – done by the study team
- 2) Terry to send out Study Information Sheets to LRNs for lay comments
- 3) Offered to help with any discussion groups in future (e.g. if study recruitment too slow)

It was agreed that having two lay PPI members on study steering groups should be routine.

However, some members of the PPI Working Group challenged the idea of sending out the Study Information Sheets to multiple individuals on LRN panels. It was suggested that, in general, a face-to-face in depth discussion of the Information Sheets would be more effective. The LRNs could explore any particular local issues around the study.

#### 3.2 RESULT study

Terry briefly outlined the study.

The main issue here was the need for clarity as to what PPI help DeNDRoN can or cannot offer to studies.

#### 3.3 DOMINO-AD study

Terry briefly outlined the study.

Lisa Curry and Jean Waters both felt that the PPI around DOMINO had been of help. However, Jean felt that there was a lesson here about getting study design right in the first place, rather than just PPI 'diagnostics' after a study has encountered problems recruiting.

#### 3.4 General comments

It would be good to write a summary of the PPI lessons of these studies for DeNDRoN Executive.

Terry McGrath should also write guidelines for PPI in specific DeNDRoN-supported studies, based around what research teams themselves would

want, and including in the development stage.

Susanne Sorensen could provide information on three charities which have been working together on what training to offer lay people. Also Terry can enquire about the guidance NCRN (National Cancer Research Network) has already produced.

#### **4 DeNDRoN 2009 Conference**

##### 4.1 Terry outlined the PPI aspects of the forthcoming conference.

Several lay people from LRNs and members of the PPI Working Group – Jean Waters, Margaret Piggott and Olivier Bazin – were due to help with sessions.

#### **5 Paper B - Developing new research sites and new patient populations**

##### 5.1 Clare Jones (North West) introduced Paper B (see Appendix).

The key issue stressed was the need for new ways for DeNDRoN to develop new research sites, by involving patients and the wider public.

Maybe PPI could help with increasing GP/Primary Care involvement in research, and with early diagnosis & early referral. There may be a training issue here for DeNDRoN. Terry thanked those LRNs who had replied to his trawl for ideas. Some respondents had felt that many of the barriers to involving new patient populations and sites were NHS regulatory bureaucracy, and questioned how patients could actually help.

##### 5.2 Another issue raised by Clare was 'Lost Populations' – including minority ethnic groups. Clare outlined work done in her LRN with Chinese and South Asian communities taking study sheets/local study info/raising awareness.

##### 5.3 The Group recognised that we must aim to work as part of a team including the third sector, and discussed how local charity groups could have a role in raising awareness, and practicalities such as access to community-based meeting rooms.

Any imaginative solutions would need to work around the fact that carers/patients are often already "worn out" with just getting basic care, let alone research involvement.

#### **6 Paper C - Handling enquiries from the public about taking part in research**

##### 6.1 Lisa Curry (North Thames) introduced Paper C (see Appendix).

The discussion focussed on the major difficulty that some patients/carers/medical charity colleagues faced trying to identify whom within DeNDRoN to contact with enquiries about possibly taking part in

England / UK research.

## 6.2 Suggestions/concerns included:

### Phone-line

- A call for a national public enquiry phone-line for DeNDRoN studies or totality of NIHR portfolio of studies

### Study-specific enquiries

- There was a call that people should either be able to contact the research team directly for more information, or, if they were in a LRN area, an LRN contact person.

### LRNs

- DeNDRoN/NIHR should, it was suggested, explain which studies are in which LRNs and spell out LRN boundaries.

### NIHR portfolio information

- It was stated that the portfolio information on the NIHR website is unfriendly and unintelligible to most lay people.

Bunia Gorelick circulated a draft PD Society webpage titled 'Take Part in Parkinson's Research' about two topics:-

- **'Take part in clinical trials'**, and
- **'Help make decisions about clinical research'**.

A crucial difficulty for the PDS webpage was that DeNDRoN has failed so far to provide any centrally-planned pathway to direct people who want clear information on what research is happening where, with a phone number and a named contact person.

Various relevant 'sectional' projects were mentioned. These included LRN local patient registers covering one or more disease areas, or medical charity information on specific studies. For example, Clare Jones circulated DeNDRoN North West's "Introduce a Friend" card. Projects undertaken in the MND and Alzheimer's Society were mentioned, including the study-specific information worked on by two DeNDRoN Dementias CSG lay members with the Alzheimer's Society.

## 6.3 Problem/Challenges raised include:

- Rapid disease-progress with some DeNDRoN diseases.
- Time and effort to manage information provision to individual enquirers at LRN or national-level, and managing self-referral
- Complex data protection issues and inclusion/exclusion criteria
- Managing those for whom no study is suitable, and the high expectations of enquirers looking very much for studies involving 'breakthrough' drugs.
- Handling enquiries across those LRNs which cover particularly large

regions, (e.g. the Truro-Gloucester issue)

- It was suggested that this was not a PPI issue, but a study recruitment issue.

6.4 Steve Iliffe said that DeNDRoN's focus for an eventual solution has started with a big vision.

DeNDRoN's vision recognises the need for some sort of systematic national registration or pre-consenting method incorporating a very broad pool of patients – i.e. many thousands of patients nationally in one scheme rather than an agglutination of local and piecemeal registers. The vision is also for this to have the potential to expand beyond usual NHS centres to include work with housing and social services.

PPI Working Group members noted, however, that local LRN registers are proving extremely useful as pilots. And also that this feeds into the issue of areas where no research-active clinicians exist to refer/alert patients to research studies.

6.5 Piers Kotting acknowledged the importance that the strong calls for better information on the NIHR portfolio, and for an improved system, are heard.

It's a huge political minefield and will take time.

He highlighted an issue around the term "patient register" – for example, in PD, current researchers often have their own networks for trials, or for good reasons will generally aim to uncover patients from the prevalent population rather than from a diagnosis register. He also explained the issue around 'Research Costs' versus 'Service Support Costs'. He also explained the Comprehensive Local Research Network (CLRN) and the good UK coverage outside LRN catchment areas, and the goal that NIHR services should be used at NHS level not LRN level.

Recruitment And Feasibility Tool

Piers described how the NIHR's current five year planning process for DeNDRoN notes suggestions from various quarters for a possible "RAFT" – the Recruitment And Feasibility Tool – but any timescales are unclear.

PPI Working Group members felt that such a system, using an ethically approved minimum database, could be a powerful research tool. There was a question why major UK medical research funders aren't funding it as a research cost.

The Group's consensus was that a message should go to the DeNDRoN Executive that RAFT has potential to be very useful. In the meantime, greater clarity as to the general public face of DeNDRoN recruitment is needed.

## **7 Paper D - PPI perspectives on how to link CSGs and LRNs**

7.1 Held over to future meeting, due to lack of remaining time.

## 8 **Any other business**

Maryrose Tarpey circulated a list of PPI links for all RDSU (Research and Development Support Units)

It was suggested in the Group that how LRNs work with RDSUs should be put on agenda for our next PPI WG meeting.

The finalised date of next meeting is now **Monday 23rd November 2009** – rather than 25th as first proposed.

## PPI Working Group Attendance Record (since start of 2008)

	25 <sup>th</sup> Feb 08	4 <sup>th</sup> Jun 08	8 <sup>th</sup> Oct 08	9 <sup>th</sup> Mar 09	29 <sup>th</sup> July 09	23 <sup>rd</sup> Nov 09
Steve Iliffe	✓	✓	✓	✓	✓	
Geoff Hanks	✓	APOLS	APOLS	✓	✓	
U Hla Htay	✓	✓	APOLS	APOLS	✓	
Jean Waters	✓	✓	APOLS	✓	✓	
Peter Webb	Peter joined in 2009			✓	✓	
Helen Santini, Huntington's Disease Association	✓	APOLS	✓	✓	APOLS	
Belinda Cupid, Motor Neurone Disease Association	✓	✓	✓	APOLS	✓	
Bunia Gorelick, Parkinson's Disease Society	✓	✓	APOLS	✓	✓	
Susanne Sorensen, Alzheimer's Society	APOLS	APOLS	David Buglar APOLS	✓ David Buglar	✓	
North East LRN	✓ Vicki Hetherington	✓ Vicki Hetherington	✓ Karen Morgan	✓ Daniel Herron & ✓ Margaret Piggott	✓ Margaret Piggott	
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	✓ Lisa Curry	✓ Lisa Curry	✓ Lisa Curry	
DeNDRoN Supplementary Resources	APOLS	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	
South Coast LRN	✓ Sandra Lawton	APOLS	APOLS	✓ Yvette Lycett	✓ Yvette Lycett	
North West LRN	✓ Angela Parker	APOLS	✓ Ruth Hunter	✓ Clare Jones	✓ Clare Jones	
Thames Valley LRN	✓ Rosemarie Streeton	APOLS	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	APOLS	
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	✓ Juniper West	✓ Juniper West	✓ Juniper West	
Douglas Mitchell	✓	✓	✓	✓	APOLS	
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	✓	✓	
Marianne Miles, NIHR Clinical Research Network	APOLS	✓ Roger Steel	✓ Roger Steel	✓ Roger Steel	APOLS	
Roger Steel, NIHR CRN					APOLS	
Terry McGrath	✓	✓	✓	✓	✓	
<p style="text-align: center;"><b>Ex-officio attendees and guests</b> Ex officio attendees may include Martin Rossor and Piers Kotting</p>			✓ Shirley Nurock - Dementias CSG	✓ Peter Webb - HD CSG ✓ Denise Wilson - DeNDRoN	✓ Piers Kotting	

## APPENDIX TO MINUTES OF JULY 2009 PPI WORKING GROUP

These were the four discussion papers.

[Discussion Paper A: Compiled by Terry McGrath, for 29th July 2009](#)

### 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.ltnc.org.uk/research\\_files/RESULT\\_study.html](http://www.ltnc.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**

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**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](http://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.

## Discussion Paper B: Compiled by Terry McGrath, for 29th July 2009

### **Developing new research sites and new patient populations**

#### **SUMMARY OF THIS PAPER**

- It asks whether PPI in Local Research Networks can help to open up new research sites or patient populations.
- It asks whether patients and carers are really able to help LRNs to overcome what are largely internal NHS bureaucratic barriers.
- It aims to prompt a discussion about how, at a time when LRNs are very busy, links with local patient groups/charities can be made as effective as possible.

### **In practice, can PPI help LRNs with identifying and developing new research sites or patient populations in geographically distinct areas that are not currently involved in clinical research?**

Local Research Networks (LRNs) sometimes want to run a study in a new setting (e.g. an NHS Trust) but find it difficult to gain agreement. Recruitment could potentially be quicker if they had more research sites to work with. Also, it may be that access to new 'sets' of patients could help.

When the challenges are often NHS hurdles and bureaucratic delays, LRNs wonder whether PPI could help. Sometimes they are busy building links with existing sites/populations; workload doesn't allow for opening up new sites from scratch. LRNs do speak at local patient groups/charities, when time allows, but would like a steer on how to make local public links in a cost effective way.

#### **For more background, here are some responses from LRNs to the above question:**

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- i. "I think we are still finding out what we can do, and haven't formulated aims so tightly, although developing new sites is high in our aspirations.
- ii. PPI as outreach, contacting, developing and nurturing new researchers - we are becoming active in this way, but the 'public' here is the clinicians."
- iii. "One of our main activities so far has been interacting with patient groups. Taking information to charity branches will likely result in some requests from patients to their usual caregivers, who may not

currently be involved in research, but we wouldn't have any information about this. So to use PPI in the way you describe, a 'geographical area' should be in mind, to gauge any impact of the PPI activity, so there could be a target for new sites and PPI one of the means of bringing it about."

- iv. "... our experiences in linking with [*Primary Care*] and GP surgeries re DOMINO [*a dementia study*] means that we now have feelers for study recruits far and wide, ..., and I'm not sure how else PPI could support this."
- v. "I've been thinking that our PPI steering members and reference panel could have a greater role in providing information about access to and recruitment to studies via the local branches of medical charities and carers groups, to publicise new sites once they have been identified and set up. The question of 'how to do this consistently and effectively' remains - of course!"
- vi. "My gut response is that we will be aware of potential new sites/populations as far as medics as PIs [*Principal Investigators*]. However it may be that when we start to make greater use of Allied Health Professionals as PIs they may have useful input."
- vii. "A good question and on the surface it feels like we should be able to work with our PPIs to open up new opportunities. However, any new opportunities being explored need to be considered in tandem with contacting the local NHS teams covering that area. If you raise the expectations of a patient group and then the local clinicians do not want to engage with us, you will be left with some very unhappy [*members of the public*]."
- viii. "... we have held two focus groups and both groups raised these kinds of issues and wanted to contribute to growing new areas but I am not sure we have been successful and joined up in how we have then taken this enthusiasm forward."

### [Discussion Paper C: Compiled by Terry McGrath, for 29th July 2009](#)

## **Handling enquiries from the public about taking part in research**

### **SUMMARY OF THIS PAPER**

- Patient representative groups/medical charities have asked for more clarity from DeNDRoN on how they should handle public enquiries about what studies are running where in DeNDRoN.
- They want the NIHR portfolio to tell them whether a study is running in each LRN
- They want a specific LRN and/or national contact to help with patient enquiries.

### **Patient representative groups/medical charities using the NIHR DeNDRoN portfolio**

The portfolio: <https://portal.nihr.ac.uk/Pages/Portfolio.aspx> is used by some medical charities when handling calls. Patient representative groups/medical charities have asked for more clarity from DeNDRoN on how they should handle public enquiries about what studies are running where in DeNDRoN.

Some patient representative groups/medical charities want the NIHR portfolio to make it easy for them to see, when talking with a patient, if a particular DeNDRoN-supported study is recruiting in the area where the caller lives. Ideally they would like the website to show, next to study title, which Local Research

Networks (LRNs) this study is running within. This would give them an idea whether to look in more detail or not to bother.

#### **Question of whom to contact**

- Some groups have said they would like to know whom to contact in each LRN.
- They have enquired whether a central DeNDRoN contact for enquiries could be useful to clarify the geographical boundaries for each LRN's recruitment area.
- It is worth noting that different LRNs work differently; some (I gather) don't want to have a system which encourages such enquiries to LRNs, whilst others are happy to.

#### **Current national information from DeNDRoN**

In practice, when calls are received at the DeNDRoN Coordinating Centre, the PPI Coordinator will often send people the document on the DeNDRoN website:

*(Go to <http://www.dendron.org.uk/pp/index.html> then click on 'Research Registers and Patient Related Organisations')*

but the PPI Coordinator usually doesn't refer calls on to LRNs. This is because most callers make clear that their interest is focussed on potential cures. If they are clearly relevant to refer on, the PPI Coordinator will do so. That document briefly covers:

- Information about possibilities for participation in research studies; What research participation means; Explains DeNDRoN and research databases, including the NIHR portfolio; Touches on inclusion and exclusion and the different phases of clinical research studies; lists medical charity websites; patient and public involvement in DeNDRoN, and groups such as INVOLVE and People in Research

#### **Wider issues**

Clearly this topic relates to the wider issue of the user-friendliness of the NIHR portfolio website, other local & national research information resources, and LRN-level 'Research Interest Registers' for interested patients and their carers.

### **[Discussion Paper D: Compiled by Terry McGrath, for 29th July 2009](#)**

## **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 Iliffe. 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.