

**Minutes of DeNDRoN PPI Working Group
30th March 2011**

Held at UCL SSEES building in London.

PRESENT

CHAIRING: **Dr. Jean Waters** - Patient Representative
Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association
Adam Smith - DeNDRoN Project Manager
Natasha Carrick - DeNDRoN Project Coordinator
Jennifer Crooks - DeNDRoN Supplementary Resources
Barbara Wilson - North East LRN
Dr. Margaret Piggott - North East LRN
Olivier Bazin - Thames Valley LRN
Ruth Hudson - North Thames LRN
Peter Gudge - System Administrator, DeNDRoN (*taking notes*)
Peter Webb - Patient Representative
Sheila Parker - East Anglia LRN
Karen Smith - East Anglia LRN
Roger Steel - PPI Manager, NIHR CRN
Dr. Steve Iliffe - Associate Director, DeNDRoN – has the PPI portfolio on the DeNDRoN Executive
Terry McGrath - PPI Co-ordinator, DeNDRoN

APOLOGIES

U Hla Htay - Patient Representative
Professor Geoff Hanks - Patient Representative who has resigned
Maryrose Tarpey - INVOLVE
Sue B - observer
Dr. Helen Santini - Care Advisor for Juvenile Huntington's Disease at the Huntington's Disease Association
Dr. Susanne Sorensen - Head of Research, Alzheimer's Society
Bunia Gorelick - Research Grants Manager, Parkinson's UK
North West LRN & South West LRN & South Coast LRN representatives (There's one formal representative due from each LRN – who can be any staff or lay member - so 'nonspecific' apologies are noted, but not named individuals)
Dr. Marianne Miles - PPI Lead, NIHR CRN
Also apologies from ex-officio invitees:
Piers Kotting and **Professor Martin Rossor**

MINUTES of 30th March 2011 meeting

1 Introductions and welcomes

Jean Waters, chairing the meeting, paid respects to Douglas Mitchell and to Minnie Htay. Everyone present also offered deepest sympathy to both families.

Jean gave apologies for Sue B from Leics, a lay person hoping to come to observe, but who was unwell.

Jean Waters reported that Professor Geoff Hanks has resigned due to pressure of national & international roles. Thanks were expressed to Geoff for his input over the years.

2 Minutes from last PPI Working Group (23rd November 2010)

- 2.1 Minutes were agreed. However, under item 3.2, concerning importance of lay input into various parts of DeNDRoN work, it was questioned whether 'feasibility' should have been classed as 'low/medium'; it was generally felt it should be categorised as 'high' importance in terms of PPI.

(NOTE: "Feasibility" concerns how practically 'doable' a study actually is for LRNs.)

Matters arising`

- 2.2 There was a request to get minutes out quicker and to put out an email announcing that they're ready. Also, action points should be included in minutes in future, and the points should be circulated within two weeks at the latest. Terry noted that action points have to date tended to be for him alone, but this may change, especially with the NIHR PPI Way Forward plans.

ACTION: Terry

- 2.3 Agenda item 4.1 - Ruth's draft example of a training package outline - should have been in the minutes, and should be added to DeNDRoN public website alongside those minutes.

ACTION: Terry

3 PPI in Study Development and DeNDRoN Projects

Terry introduced the overall topic of the need to plan practical PPI around the NIHR 'Dementia Themed Call' and in Study Development more generally

MAIN POINTS:

- **There's a growing demand for PPI (e.g. from DeNDRoN Writing**

Groups) around study development. In DeNDRoN previously this has borne a low emphasis – because the emphasis was instead on study delivery. In this new approach, PPI in study development will become “core business” across DeNDRoN.

- **The NIHR ‘Dementia Themed Call’ is now having a big impact.** Terry is being required to manage patient and carer involvement in working up a range of ideas for clinical research to becoming grant applications. If DTC applicants don’t ask for help, TM will contact them offering PPI – as a ‘managed service’ if the study has Writing Group support.
- **There are growing calls for DeNDRoN to provide PPI around a whole range of research issues** on the horizon more generally, not related to specific study delivery.

3.1 Steve Iliffe confirmed that DeNDRoN recognises a greatly increased requirement for PPI in the design phase of research as well as in the implementation of research. Such issues may well inform the content of future PPI Working Group meetings and DeNDRoN PPI Forum gatherings.

Terry reported that he is currently also meeting with, or taking with, the PPI Leads across all ten RDSs (Research Design Services) in England, to explore the overlap with RDS input.

The challenge is to get the balancing act right about how much help is right to offer to study teams which have signally failed to embrace PPI up to this time. Steve Iliffe said that ‘if researchers have not got their act together now, will be hard to convince them now about PPI’.

3.2 **PPI specifically for the ‘Dementia Themed Call’ (DTC)**

DH wants more research applications around dementias in all the NIHR funding streams. Terry noted a huge unknown factor – which is how many of DTC applicants will want PPI help, and what PPI.

Much of the work will be provided by a DeNDRoN ‘managed service’ - before full bids go in - using focus groups, or surveys, or one-to-one interviews, or finding people for reference panels/boards, etc. TM personally recommended the use of very small focus groups or one-to-one interviews as a ‘holographic’ technique but obviously DeNDRoN is not prescriptive about this method.

Terry is producing researcher guidance on these PPI methods to go on the DeNDRoN website, as well as offering this ‘hands on’ assistance directly to researchers. To qualify for the help, studies have to have DeNDRoN Writing Group support.

TM has contacted DeNDRoN LRNs asking what help might be forthcoming from LRNs. DeNDRoN CC can pay for appropriate and attractive venues.

There was concern expressed that LRNs need to be willing and active to avoid a risk of Terry taking on too many commitments. LRN representatives said that the sooner there were specific plans for LRNs, the better.

- 3.3 Terry noted that some lay people are prepared to travel long distances for meetings as they find input into study development so rewarding. This means that LRN meetings will attract people widely from elsewhere.
- 3.4 Roger Steel said that managing this PPI could be multifaceted, with DeNDRoN developing a coordinated mindset that all its lay people, and combined knowledge and skills are a “commonwealth” across all the LRNs & C.C. However, different LRNs would have different ways of inputting.
- 3.5 Belinda Cupid reported that MNDA had not been approached with information about the DTC. It was noted that, although joint work is already going on with the Alzheimer’s Society and DeNDRoN, the DTC covers dementia across the range of neurodegenerative diseases, and the importance of cooperation and links with all medical charities was reaffirmed.

3.6 **PPI in Study Development and DeNDRoN projects more generally**

For a whole range of research issues, outside of specific study issues, there is growing pressure to have PPI input, for example:

- generic interventional issues: e.g.: the drug company issue of balancing risk/benefit in any potential interventions in early so-called ‘prodromal’ stages of neurodegenerative diseases.
- DeNDRoN projects: e.g. patient registers, care home research.

It was also felt that DeNDRoN Clinical Studies Groups need to ensure adequate PPI input into the ongoing work of Writing Groups.

3.7 **PROJECTS**

Adam Smith, Project Manager, gave an introduction to some specific new DeNDRoN projects, focusing on ones in which PPI is likely to develop:

- INTERACT: interacting with the NHS in areas without DeNDRoN Local Research Networks
- REGISTERS (or “RAFT”): volunteer patient registers
- ENRICH: research into care home settings

Note: Some of the slides are viewable alongside these minutes on the internet. It includes Adam’s/Natasha’s email addresses.

- 3.8 There was discussion about PPI to date for these projects. Each individual project board has appropriate lay representation.

INTERACT:

For this project, PPI seems particularly important, especially about how INTERACT affects clinical services. It was felt the most sensible level for such PPI will be within LRNs.

- It was suggested that INTERACT should be empowering patients, to be able to ask to be on research projects; and informing the public about the research going on.

REGISTERS/("RAFT"):

One potential vision is towards a 'federated network of local registers'.

- It is noted how differently all the various registers are run (e.g. North East and North Thames's 'DemReg'). Issues discussed included the amount of staff time and other resources needed to manage data and communications for registers, such as whether labour-intensive home visits are included.
- PPI would be an important way of assessing these issues.

ENRICH:

It was felt that particularly for ENRICH there should need to be a critique/assessment of the PPI aspects fairly soon.

3.9 G.P. involvement:

Both for INTERACT and for REGISTERS/("RAFT"), it was acknowledged that it can be a challenge to get GPs involved. For example, Margaret Piggott, who explained the North East example of a register, said there's been little response from GPs for the register.

- A patient representative on the group said there's a strong need to kick back against the lack of productive links with GPs and forge stronger links with them. It was felt that PPI input could be focussed to help create a culture change; there shouldn't really be a necessity to ask GPs to give permission – just to be kept informed.

3.10 Adam and Natasha's email addresses are added to the slides, and people are encouraged to contact them with any views, suggestions and questions.

4 Update on NIHR PPI Way Forward

Roger Steel, NIHR PPI Manager, outlined the main points and latest developments in the NIHR PPI Way Forward process.

Note: NIHR PPI Way Forward Report is viewable alongside these minutes on the internet.

4.1 Roger said the report has four recommendations, which emerged from the wide consultation, for achieving a broad common framework which uses resources more wisely and improves the impact of patients, carers and the public involvement:

- Identify and target activity in a commonly agreed framework
- Develop better cross-network and cross-NIHR collaboration
- Formalise evidence gathering and dissemination
- Integrate learning and development opportunities

4.2 Assuming agreement of the business case and PPI budgeting by the DH, we

are now in the implementation phase. A key theme will be about embedding PPI as core business in delivering research, with shared leadership (including by DeNDRoN) so that learning and training about PPI will be spread across the CRN.

- 4.3 Terry stressed that one of the key points in the NIHR PPI Programme is that DeNDRoN will have to develop an Annual Plan which matches the recommended NIHR themes.
- There is also an emphasis on effective partnerships with other organisations. So DeNDRoN's annual plan will need specifics as to how DeNDRoN plans to work with medical charities, RDS (Research Design Services), etc. It is important that DeNDRoN sets its own objectives realistically – so we don't have objective we're not sure about delivering.
 - Terry will be part of the team working to develop this until March 2012. There will be pressure over the next few months to get things moving.

5 Communications issues

Issues of comms and 'awareness-raising' around research and recruitment to studies. Terry reminded everyone that this was a strong theme from last year's PPI Forum.

- 5.1 In East Anglia DeNDRoN, an idea came from patient/carer focus group to hold a stall in a shopping centre to publicise a specific Alzheimer's disease study where local recruitment was very low.
- We held an all-day stall in a Peterborough Shopping Centre on a Sunday, funded by the drug company running the study. We had ethics approval for this approach, but company said DeNDRoN had to use DeNDRoN-themed stand not company stand.
 - It didn't work; there was very little interest, and no-one who met appropriate criteria.
- 5.2 Various other LRN attempts at recruitment publicity were reported.
- One LRN had an advert in a paper for a study, and no-one was recruited from this.
 - It was said that when publicity is more appropriately targeted (brain donation and another pharmaceutical study were examples mentioned) it is much more successful. And focussing on particular centres (Addenbrooke's Hospital was an example mentioned) seemed more successful for recruiting.
 - Regulatory and ethical issues controlling publicity for individual studies were quite challenging.
- 5.3 Use of the internet generally, and "social media" such as Facebook, were

discussed. Lack of privacy was seen as a risk.

- The potential impact of these remains unclear, but it was understood that in some circumstances pharmaceutical companies use social media for recruiting people to commercial trials.
- Different medical charities have different experiences of using social media. MNDA and HDA both have some success in use of message forums, etc.
- NIHR Clinical Research Network has done work on what can be effective, and the limitations.

5.4 Jean Waters noted that this all strengthens the case for registers.

6 Following all the above discussions, plan training and PPI Forum meeting this autumn

Suggestions for this year's PPI Forum, e.g. what training, who should fund it and who should deliver it, what scope for joint work with medical charities, and discussion re any clashing dates.

6.1 Terry urged that the PPI Forum should be towards the end of the year, especially because encouraging clinicians to attend takes a long time.

We would like ideas as to what can be discussed. All to send in any ideas please.

ACTION: ALL to consider ideas for PPI Forum, and email Terry with any suggestions

Two very popular suggestions were:

1. Training around reviewing grant applications (suggested in the light of the NIHR Dementia Themed Call). This should focus not on the formal process done by funding bodies with PPI input, but the earlier phase before applications go in, around "developing and tweaking applications".
2. Reviewing failing studies. However, it was noted that this could be difficult for many studies because:
 - drug companies may be reluctant to involve PPI
 - drug companies tend to insist on lots of exclusion criteria
 - convincing clinicians & researchers to come along to discuss failing studies is not easy

Additional suggestions were:

3. INTERACT – but only if there's something concrete about it to work through.
4. ENRICH – but only if there's something concrete.

6.2 There was a clear call that Parkinson's disease, motor neurone disease, and Huntington's disease don't get forgotten in planning content of the day.

6.3 Working Group members should be requested to email Terry any UNSUITABLE dates in September/October/November 2011.

ACTION: Terry to remind ALL to email Terry with any unsuitable dates

7 Any other business

7.1 There was discussion about who should be the Chairperson for this meeting. Someone made a suggestion that Jean Waters be invited to chair. Terry will ask for nominations by email. .

ACTION: Terry

7.2 Terry suggested we reduce the incidence to two meetings per year. Maybe all consider and discuss for next meeting.

ACTION: ALL

8 Date of next meeting

The agreed date for the next meeting is Wednesday 13th July 2011.

PPI Working Group Attendance Record

	25 th Feb 2008	4 th Jun 2008	8 th Oct 2008	9 th Mar 2009	29 th Jul 2009	23 rd Nov 2009	15 th Mar 2010	13 th Jul 2010	23 rd Nov 2010	30 th Mar 2011	13 th Jul 2011
Steve Iliffe	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Douglas Mitchell	✓	✓	✓	✓	APOLS	✓	APOLS	✓	APOLS	R.I.P.	
Geoff Hanks	✓	APOLS	APOLS	✓	✓	APOLS	✓	APOLS	APOLS	APOLS	
U Hla Htay	✓	✓	APOLS	APOLS	✓	APOLS	✓	✓	✓	APOLS	
Jean Waters	✓	✓	APOLS	✓	✓	✓	✓	✓	✓	✓	
Peter Webb	Peter joined in 2009			✓	✓	APOLS	✓	✓	✓	✓	
Helen Santini, H.D.A.	✓	APOLS	✓	✓	APOLS	APOLS	APOLS	APOLS	APOLS	APOLS	
Belinda Cupid, M.N.D.A.	✓	✓	✓	APOLS	✓	APOLS	✓	✓	✓	✓	
Bunia Gorelick, P.U.K.	✓	✓	APOLS	✓	✓	APOLS	✓	APOLS	✓	APOLS	
Susanne Sorensen, A.S.	APOLS	APOLS	D Buglar APOLS	✓ D Buglar	✓	✓	✓	APOLS	APOLS	APOLS	
North East LRN	✓ V Hetherington	✓ V Hetherington	✓ K Morgan	✓ D Herron & M Piggott	✓ M Piggott	✓ M Piggott	✓ M Piggott	✓ M Piggott	✓ J Pearson & M Piggott	✓ B Wilson & M Piggott	
North Thames LRN	✓ K Judd	✓ C O'Keefe	✓ L Curry	✓ L Curry	✓ L Curry	✓ K Judd	✓ K Judd & L Curry	✓ K Judd & R Hudson	APOLS	✓ R Hudson	
DeNDRoN Supplementary Resources	APOLS	✓ J Keylock	✓ J Keylock	✓ J Keylock	✓ J Keylock	✓ J De Souza	APOLS	APOLS	✓ J De Souza	✓ J Crooks for J De Souza	
South Coast LRN	✓ S Lawton	APOLS	APOLS	✓ Y Lycett	✓ Y Lycett	✓ Y Lycett	APOLS	✓ R Chandler	✓ R Chandler	APOLS	
North West LRN	✓ A Parker	APOLS	✓ R Hunter	✓ C Jones	✓ C Jones	APOLS	✓ C Jones	✓ C Jones	APOLS	APOLS	
Thames Valley LRN	✓ R Streeton	APOLS	✓ O Bazin	✓ O Bazin	✓ O Bazin	✓ O Bazin	✓ O Bazin	✓ C Cox & A Silk	✓ J Cross & O Bazin	✓ O Bazin	
South West LRN	✓ D Howcroft	✓ D Howcroft	✓ D Howcroft	✓ D Howcroft	APOLS	✓ A Wright	✓ A Wright	✓ A Wright	✓ A Wright	APOLS	
East Anglia LRN	✓ J Wilson	✓ C Lindsay	✓ J West	✓ J West	✓ J West	APOLS	✓ K Smith	APOLS	✓ S Parker	✓ S Parker & K Smith	
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	✓	✓	APOLS	APOLS	✓	✓	APOLS	
Marianne Miles, NIHR CRN	APOLS	✓ R Steel	✓ R Steel	✓ R Steel	APOLS	✓ R Steel	✓ R Steel	APOLS	APOLS	✓ R Steel	
Roger Steel, NIHR CRN					APOLS			APOLS	APOLS		
Terry McGrath	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

Ex-officio attendees and guests and observers

- 8th Oct 2008: Shirley Nurock - Dementias CSG
- 9th Mar 2009: Denise Wilson - DeNDRoN
- 29th Jul 2009: Piers Kotting
- 23rd Nov 2009: Martin Rossor & Piers Kotting
- 15th Mar 2010: Martin Rossor (morning)
- 23rd Nov 2010: Graham Thorp, Adam Smith, Piers Kotting & Caroline Struthers
- 30th Mar 2011: Adam Smith & Natasha Carrick
- 13th Jul 2011: