
**Minutes of DeNDRoN PPI Working Group
23rd November 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
Dr. Jean Waters - Patient Representative
Professor Douglas Mitchell - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN
Dr. Susanne Sorensen - Head of Research, Alzheimer's Society
Olivier Bazin - from Thames Valley DeNDRoN
Katy Judd - from North Thames DeNDRoN
Abigail Wright - from South West DeNDRoN
Jenny De Souza - from DeNDRoN Supplementary Resources
Yvette Lycett - from South Coast DeNDRoN
Dr. Margaret Piggott - from North East DeNDRoN
Roger Steel - PPI Manager, NIHR CRN
Professor Martin Rossor - Director, DeNDRoN
Piers Kotting - Assistant Director, DeNDRoN
Terry McGrath - PPI Co-ordinator, DeNDRoN
Andrew Rutherford - (*minutes*) - Network Co-ordinator, DeNDRoN

APOLOGIES

Professor Geoff Hanks - Patient Representative
U Hla Htay - Patient Representative
Peter Webb - Patient Representative
Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association
Bunia Gorelick - Research Grants Manager, Parkinson's Disease Society
Clare Jones - from North West DeNDRoN
Juniper West - from East Anglia DeNDRoN
Daniel Herron - North East LRN Manager
Maryrose Tarpey - Public Involvement Adviser, INVOLVE
Dr. Marianne Miles - PPI Lead, NIHR CRN
Dr. Helen Santini - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association

MINUTES

1 Introductions and welcomes

2 Minutes from last PPI Working Group

2.1 Correction: Roger Steel didn't attend. The minutes were otherwise agreed to be accurate.

2.1 Matters Arising – on agenda

2.2 Survey

Terry introduced the survey report, stressing the recommendation at the end of the report to not repeat in its current form, saying it would repeat what we've already found – that there should be more opportunities for lay people to be involved in study set up and running. If a repeat were initiated, it was felt it should ask additional 'underlying' questions such as whether researchers felt the PPI was sufficient and what the PPI had aimed to achieve.

Terry again thanked the South West LRN for their help.

There was a discussion about what exactly "lay" meant in such circumstances, noting that it covered a hugely diverse range of people.

The discussion opened out to recognise the need for 'evaluation' of PPI. Looking at certain examples of certain case studies of PPI in research design and implementation is probably the most useful approach, but it was noted that the life cycle of a piece of research could be a decade so evaluation could be a very slow process.

One suggestion was that it might be worth a punt to consider a randomised controlled trial of PPI in study processes (despite the 'problem of equipoise'.)

This should be on the agenda for the next PPI Working Group on 15th March. It will be a useful time because the NIHR process looking at the way forward for PPI will have kicked in by then.

A third to a half of those that responded said that PPI had made a significant contribution; however, the group asked how PPI can make a contribution if it is not built into study design.

2.3 Mustardd-PD

Terry outlined how the new Mustardd Parkinson's Disease study information sheets had been sent out to PPI 'champions' in each LRN and forwarded by them to lay people for comments. Returned comments were distilled into a report forwarded to the Chief Investigator - who has said the lay people's views will definitely affect the wording on information leaflets.

LRN staff present felt this worked well nationally and was encouraging – but there was debate about the pro’s and con’s of running face to face group discussions rather than simply mailing individual lay people for comments.

2.4 “RAFT” – acronym for Recruitment and Feasibility Tool

Jean reported that the MND patient disease register went live hosted by MND association with sign-posting to DeNDRoN via the pro-forma.

It was commented that the phrase ‘RAFT’ – ‘Recruitment and Feasibility Tool’ – is not synonymous with a list of willing volunteers.

It was noted that DeNDRoN cannot fund registers as such; ‘RAFT’ is an overarching acronym useful for DeNDRoN internally, but communicating this suitably to the public is still a work in progress, trying to find a middle ground. There is an advantage of going through disease-specific organisations to avoid some related problems.

Other matters arising

2.5 Item 2.1 External review of DeNDRoN

Steve Iliffe said a meeting with DH is scheduled for December discussing study recruitment in social care & care homes.

2.6 Item 2.4 “Payment for Time”

Terry reiterated the point in previous minutes explaining that LRNs cannot offer “payment for time” for LRN-level lay involvement; as the DH has only provided a budget for this for national PPI.

2.7 Item 3.2 RESULT study

Jean Waters said that the Study Reference Group had met for the first time. They were grateful to DeNDRoN for facilitating this.

2.8 Item 3.4 Summary of PPI in specific studies

Terry has now written this summary and a PPI poster describing it will be presented at NIHR conference in January 2010.

2.9 Item 4.1 PPI aspects of recent DeNDRoN conference

General feedback was that the overall PPI input was well appreciated. However, Olivier noted that the PPI Question Time workshop had been unchallenging.

3 DeNDRoN 5-year plan

3.1 Terry introduced discussion of the ‘Key Questions’ section relating to PPI Working Group, which is found at the end of the ‘DeNDRoN Vision, Purpose, Aims, Key Priorities And Targets’ paper.

The overarching discussion was about how PPI can be part of achieving

these targets.

Papers circulated in advance included:

- DeNDRoN vision, purpose, aims, key priorities and targets - 5 year plan summary for PPI working group
- Summary of PPI Review for DeNDRoN PPI Working Group November 2009
- There was also a link supplied to the full 'DeNDRoN 5 year plan

3.2 Targets 1.1, 1.2, and 1.3

People agreed that there had been studies where DeNDRoN would have liked the study to open up in new sites (e.g. Darlington), suggesting that if patients had been engaged, they could potentially have helped achieve that. There are areas that are deserts.

Medical charities might help in building an "internal campaign force" to push to open new sites. A DeNDRoN aspiration is that individuals not leave specialists' surgeries until they know what research there is, and if not offered, a minority will be pushy. A DeNDRoN task is therefore for individuals and groups to know what going on, pick this up and agitate NHS Trusts. Susanne suggested that the mechanism for change more likely happen through central offices. Individual patient letters could also be helpful, and 'rights' in the NHS Constitution may help provide leverage for patients.

Although time constraints on what PPI is possible were noted, it was stated that the time problem isn't so great when seen over the longer period.

The need for different approaches in the different disease areas was noted, with motor neurone disease as an example.

To achieve some targets, more accessible portfolio information is needed. Portfolio Two is being developed to be more easily publically accessible, and more useful for GPs.

Steve asked if we need to develop some communication models for LRNs to try out. Work is local and incremental, and it was generally agreed that DeNDRoN needs to develop different models/route maps and try them out. An LRN could "take on" a specific disease, or pilot one local area.

Publicity campaigns raise expectations, and only a small fraction of patients on registers will get into a clinical research study. So expectation management was seen as very important.

3.3 Targets 2.1, 2.2, 2.3, 2.4 and 2.5

The key issues here were seen as "Feasibility, Feasibility, and Feasibility", and PPI should have ways for helping in LRN feasibility assessments.

If study design flawed, it will not recruit to target. We need more PPI in how to write better funding applications.

The issue of co-production was raised, as a way to address the problem of studies being rejected. Such co-design PPI processes would generally need

to be done anonymously if possible, and work would be needed to set up pre-meeting preparatory briefings for lay people before design sessions to allow for best use of time. It was noted that charities which have expertise in PPI in study design can help with workshops and training.

3.4 Targets 3.1, 3.2, and 3.3 (Industry)

Medical charities find it challenging to promote an industry study. Can be problems later being linked with a particular product. But during study patients happy to be in industry trials.

Obstacle to PPI involvement not as great as we thought. However, individual PPI comments on protocols wouldn't carry as much weight and respect within industry as would a managed PPI process.

3.5 **Paper: Summary of PPI Review for DeNDRoN PPI Working Group November 2009**

This wasn't discussed due to time pressure.

Please read and feed comments to Terry out of meeting.

4 **Proposal for PPI Forum discussions in early 2010**

Terry McGrath outlined some ideas already developed for the annual national DeNDRoN PPI Forum meeting due to take place early 2010.

The proposed theme was changed from 'what lay people need from DeNDRoN' to focussing on discussing the 5-year plan and 'what role will you be playing in achieving this and how can DeNDRoN help you do this' or even more straightforwardly, 'how can PPI help to deliver DeNDRoN's targets'.

Also it needs to look at how "DeNDRoN can be more than these targets", for example by developing the involvement culture in dementia and neurodegenerative disease clinical research. The group agreed that this should be done by developing an action plan, doing the work and getting going.

- 4.1 The next PPI working group meeting is already confirmed as 15th March 2010, and Terry had earlier suggested that the PPI Forum should follow this on 16th or 17th March. However, it was widely suggested that the PPI Forum meeting needs to be before the next Working Group, so a new date will be sent out.

5 **Any other business**

- 5.1 The finalised date of next meeting is now **Monday 15th March 2010**.

PPI Working Group Attendance Record (since start of 2008)

	25 th Feb 08	4 th Jun 08	8 th Oct 08	9 th Mar 09	29 th July 09	23 rd Nov 09	15 th Mar 10
Steve Iliffe	✓	✓	✓	✓	✓	✓	
Douglas Mitchell	✓	✓	✓	✓	APOLS	✓	APOLS
Geoff Hanks	✓	APOLS	APOLS	✓	✓	APOLS	
U Hla Htay	✓	✓	APOLS	APOLS	✓	APOLS	
Jean Waters	✓	✓	APOLS	✓	✓	✓	
Peter Webb	Peter joined in 2009			✓	✓	APOLS	
Helen Santini, Huntington's Disease Association	✓	APOLS	✓	✓	APOLS	APOLS	
Belinda Cupid, Motor Neurone Disease Association	✓	✓	✓	APOLS	✓	APOLS	
Bunia Gorelick, Parkinson's Disease Society	✓	✓	APOLS	✓	✓	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	✓ Margaret Piggott	
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	✓ Lisa Curry	✓ Lisa Curry	✓ Lisa Curry	✓ Katy Judd	
DeNDRoN Supplementary Resources	APOLS	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny De Souza	APOLS
South Coast LRN	✓ Sandra Lawton	APOLS	APOLS	✓ Yvette Lycett	✓ Yvette Lycett	✓ Yvette Lycett	APOLS
North West LRN	✓ Angela Parker	APOLS	✓ Ruth Hunter	✓ Clare Jones	✓ Clare Jones	APOLS	
Thames Valley LRN	✓ Rosemarie Streeton	APOLS	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	APOLS	✓ Abigail Wright	
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	✓ Juniper West	✓ Juniper West	✓ Juniper West	APOLS	
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	✓	✓	APOLS	
Marianne Miles, NIHR Clinical Research Network	APOLS	✓ Roger Steel	✓ Roger Steel	✓ Roger Steel	APOLS	✓ Roger Steel	
Roger Steel, NIHR CRN					APOLS		
Terry McGrath	✓	✓	✓	✓	✓	✓	
<p style="color: red; text-align: center;">Ex-officio attendees and guests</p> <p style="text-align: center;">Ex officio attendees may include Martin Rossor and Piers Kotting</p>			✓ Shirley Nurock - Dementias CSG	✓ Peter Webb - HD CSG ✓ Denise Wilson - DeNDRoN	✓ Piers Kotting	✓ Martin Rossor ✓ Piers Kotting	