
Minutes of DeNDRoN PPI Working Group 25th Feb 2008

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
Dr. Helen Brewer - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association
Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association
Bunia Gorelick - Research Grants Manager, Parkinson's Disease Society
Vicky Hetherington - from North East DeNDRoN
Deborah Howcroft - from South West DeNDRoN
Katy Judd - from North Thames DeNDRoN
Piers Kotting - Assistant Director, DeNDRoN
Sandra Lawton - from South Coast DeNDRoN
Professor Douglas Mitchell - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN
Angela Parker - from North West DeNDRoN
Professor Martin Rossor - Director, DeNDRoN
Rosemarie Streeton - from Thames Valley DeNDRoN
Maryrose Tarpey - Public Involvement Adviser, INVOLVE (www.invo.org.uk)
Jennifer Wilson - from East Anglia DeNDRoN
Terry McGrath - PPI Coordinator, DeNDRoN and **Andrew Rutherford** - taking notes

APOLOGIES as received:

Dr. Marianne Miles - Patient and Public Involvement Lead, UK Clinical Research Network
Dr. Susanne Sorensen - Head of Research, Alzheimer's Society

MINUTES

1 INTRODUCTIONS AND WELCOMES

1.1 This included brief reports on PPI-related activity from LRN representatives.

2 MINUTES FROM LAST PPI WORKING GROUP (25/02/08)

2.1 Minutes were accepted with two corrections.

- Item 5.3 on 'Study Feasibility' section of 'Analysis of Priority Areas' is

wrong. The Working Group had, in fact, agreed to remove the line recommending use of Patient/Carer Advisory Panels.

- Item 5.4 typing error: Should read “CSGs may have an input...”

2.2 Discussion on amended document: ‘An Analysis of Priority Areas for PPI in DeNDRoN’

As well as the above correction, it was felt that the section on ‘Feasibility and Gaps’ needn’t name all the individual groups, just simply read: “Clinical Studies Groups and Special Interest Groups”.

It was agreed that the finalised version should be put on the public website with a shortened introduction section, and circulated to LRNs.

3 ‘ONE YEAR REMIT’ FOR PPI WORKING GROUP: Up to April 2009

- 3.1 Terry McGrath introduced the ‘One Year Remit’ for the PPI Working Group, which he had drafted for agreement. It has shorter term objectives than the longer term remit previously discussed.

3.2 The following comments were raised:

The target of June 08 for two patient/public representatives on all LRN steering committees is probably overoptimistic. It is essential to ensure LRN Steering Committees will be welcoming, so hurrying to appoint people is wrong, and sufficient support needs first to be in place to ensure retention of appointed people.

The Operational Steering Group (OSG) was felt to be “a robust environment” so it may take longer to incorporate lay representation.

Targets on evaluation were seen as imperative. This isn’t just to record of the richness of people’s input, or for the UKCRN external assessment, but to start to assess the precise impact of PPI on DeNDRoN’s output, even at this early stage in many DeNDRoN activities and studies. It was generally felt that a useful first step would be a survey of attitudes to PPI within DeNDRoN, followed by a 360° appraisal of the PPI “state of play” in time for the UKCRN assessment. There was also comment on the need to engage with “non-interested” clinicians.

For the target of December 08, a practical PPI toolkit with a central focus on increasing accrual would be more welcome than ‘best practice guidelines’.

3.3 The following amendments were decided:

Change the evaluation targets to an earlier survey of attitudes to PPI within DeNDRoN, followed, in time for the UKCRN assessment, by a 360° appraisal of the PPI “state of play”.

Change the ‘best practice guidelines’ to a ‘practical PPI toolkit’.

- 3.4 The remit, with incorporation of the above amendments, was agreed.

4 DEVELOPING PPI IN LOCAL RESEARCH NETWORKS

4.1 There was strong support for involving lay members on LRN steering committees. The document - 'Guidance on Recruitment of Patient/Public Members on DeNDRoN Local Research Network Steering Committees' - was approved.

4.2 The issue of wider patient and public involvement in LRNs was discussed.

There was felt to be a growing need for people to have informal opportunities to be part of the local network. It was generally envisaged that all LRNs would develop an informal database or 'panel' of interested people, who are not formal members of LRN committees.

Suggestions for informal involvement included:

- Individuals helping with raising awareness with local medical charities or local organisations, such as a Research Development Service Unit
- Help with editing local newsletters/leaflets
- Input in planning/delivering DeNDRoN events
- Open meetings or focus groups on pertinent local questions

However, there were some caveats:

Baseline For Keeping In Contact - There must be a definite baseline for keeping in contact with registered people on a local database. For example, as a minimum a six-monthly newsletter, and an opportunity to meet together once a year.

Study Feasibility - It must be made clear to all that study feasibility is unlikely to be a significant part of PPI at LRN level.

Duplication With Medical Charities - Although there might occasionally be a role in writing a lay description for any locally-developed research proposals, there's a need to avoid duplication with such work that might be being done in a medical charity.

5 UPDATE ON WORK AROUND PPI IN COMMERCIAL STUDY ADOPTION

5.1 Terry McGrath introduced the topic. The main challenges are the rapid speed of 'in principle' two-week decision-making and commercial confidentiality issues. There is some work being done at UKCRN level about the legal issues around confidentiality and legal individual indemnity for lay members.

5.2 It was felt that, in DeNDRoN, involvement of lay members could focus initially on inviting the already-established members of the relevant CSGs to be involved in rapid decisions, as those CSGs are governed by confidentiality agreements.

The best focus for wider involvement of lay members in commercial studies

was felt to be helping in decisions in LRNs about whether the LRN is capable of running the study at local sites. The four week turnaround for decisions was felt to allow time for this involvement.

6 PLANNING THE CONTENT OF FORTHCOMING EVENTS

6.1 PPI Forum Development Day

The plans for the event were welcomed, with some proposals made:

- May be best to avoid too much clinical content, so as to provide more time for sharing of experiences to date, and more debate about what people understand to be their roles.
- Break up into smaller workshops.
- Have a session looking at toolkit solutions.
- Other suggestions included having a charismatic speaker, and a workshop on training needs.

6.2 DeNDRoN Annual Conference

Plans to date were discussed.

It was noted that in the plenary discussion of how early identification of patients could contribute to research, the implications of the hereditary nature of HD should not be overlooked.

7 PREPARING FOR THE DEPARTMENT OF HEALTH AUDIT OF DENDRON IN JAN 2009

7.1 The plans for the external assessment of DeNDRoN were outlined.

In terms of PPI aspects, as well as simply reporting lay representation on committees, it was felt that a key factor should be demonstrating, as much as is possible, how PPI mechanisms are improving accrual and retention to DeNDRoN studies.

7.2 It was noted that a formal statement submitted this Autumn from the PPI Working Group might well form part of the DeNDRoN submission for this.

8 ANY OTHER BUSINESS

8.1 U Hla Htay felt that DeNDRoN should have more direct links with Alzheimer's Society branches.

8.2 There was a request for name badges at the next meeting.

PPI WORKING GROUP ATTENDANCE RECORD

	Monday 25th February 2008	Wednesday 4th June 2008	Wednesday 8th October 2008
Steve Iliffe	✓		
Geoff Hanks	✓	APOLOGIES	
U Hla Htay	✓		
Jean Waters	✓		
Helen Brewer, Huntington's Disease Association	✓	APOLOGIES	
Belinda Cupid, Motor Neurone Disease Association	✓		
Bunia Gorelick, Parkinson's Disease Society	✓		
Susanne Sorensen, Alzheimer's Society	APOLOGIES	APOLOGIES	
North East LRN	✓ Vicky Hetherington		
North Thames LRN	✓ Katy Judd		
DeNDRoN Supplementary Resources	APOLOGIES		
South Coast LRN	✓ Sandra Lawton		
North West LRN	✓ Angela Parker	APOLOGIES	
Thames Valley LRN	✓ Rosemarie Streeton	APOLOGIES	
South West LRN	✓ Deborah Howcroft		
East Anglia LRN	✓ Jennifer Wilson		
Douglas Mitchell	✓		
Maryrose Tarpey, INVOLVE	✓	APOLOGIES	
Marianne Miles, UK Clinical Research Network	APOLOGIES		
Terry McGrath	✓		

Ex officio attendees not recorded above include Martin Rossor, Piers Kotting, and minute taker.

DIARY DATES

Next PPI Working Group

- MRC Headquarters, 20, Park Crescent, London: Wednesday 8th October

DeNDRoN Annual Conference

- Hilton, Newcastle-Gateshead: 14th October 2008
- Some people will be attending DeNDRoN meetings the day before – 13th – then staying in a nearby hotel.