
**Minutes of DeNDRoN PPI Working Group
4th June 2008**

PRESENT

Dr. Steve Iliffe - Chairperson, DeNDRoN Associate Director who has the PPI portfolio on the Executive
U Hla Htay - Patient Representative
Dr. Jean Waters - Patient Representative
Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association
Bunia Gorelick - Research Grants Manager, Parkinson's Disease Society
Vicki Hetherington - from North East DeNDRoN
Deborah Howcroft - from South West DeNDRoN
Jenny Keylock - from DeNDRoN Supplementary Resources
Catherine O'Keeffe - from North Thames DeNDRoN
Caroline Lindsay - from East Anglia DeNDRoN
Piers Kotting - Assistant Director, DeNDRoN
Professor Martin Rossor - Director, DeNDRoN (for part)
Professor Douglas Mitchell - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN
Roger Steel - PPI Manager, UKCRN
Terry McGrath - PPI Coordinator, DeNDRoN
Andrew Rutherford - DeNDRoN Network Coordinator - taking notes

APOLOGIES as received:

Professor Geoff Hanks - Patient Representative
Dr. Helen Brewer - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association
Dr. Marianne Miles - PPI Lead, UKCRN ~ but Roger Steel attended
Dr. Susanne Sorensen - Head of Research, Alzheimer's Society
Maryrose Tarpey - Public Involvement Adviser, INVOLVE (www.invo.org.uk)
Sandra Lawton - from South Coast DeNDRoN
Angela Parker - from North West DeNDRoN
Rosemarie Streeton - from Thames Valley DeNDRoN

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1 Introductions and welcomes

2 Minutes from last PPI Working Group (25/02/2008)

2.1 Minutes were accepted with the following correction.

- Debbie Howcroft was present at the last meeting

2.2 **Matters arising**

Under Sect. 2.2, Terry McGrath had put the finalised version of the agreed 'Analysis of Priority Areas for PPI...' on the DeNDRoN public website, and circulated to LRNs. However it was commented that it still mentions "Patient/Carer Advisory Panels" as a model for Feasibility – which we had previously asked to remove. TM will remove.

Under Sect. 4.2, the unexplained jargon 'RDSU' means Research Development Support Unit.

Study Feasibility:

Also under Sect. 4.2, the discussion was revisited around whether 'Study Feasibility' was considered unlikely to be a significant part of PPI at LRN level. Whilst it is agreed that most study protocols reach the LRN already set, and protocol development happens less at LRN level, Piers Kotting stressed that PPI could still help with developing feasibility in various ways, such as helping to set up Memory Clinics where they are currently lacking.

Industry:

Under Sect. 5, Roger Steel mentioned the UKCRN generic work he's doing on Industry Study Adoption.

2.3 Annual Conference: patient/carers suggestions from Newcastle:

Terry McGrath mentioned his gratitude to people who had attended a meeting in Newcastle about what to put in to the conference from their perspective. Their suggestion for a session involving physiotherapists was welcomed, but may be more useful if it avoids an 'experiential' format and explore a broader focus than the original Parkinson's disease focus suggested. **Vicki Hetherington is happy to help liaise with physiotherapists on this.**

The calls for patients to help with chairing conference and for a relaxing 'Quiet Room', were supported. **Terry to look into both.**

2.4 Annual Conference: PPI Workshop:

There was much support for the plan for this to focus on PPI in research implementation, rather than in study design.

2.5 Remit of the PPI Working Group (Agenda Paper 2 was circulated):

Correction second para: For 'May', read 'June'. With this amendment, it was approved.

Jean Waters noted the aim to have patient representatives in all LRNs and asked what the progress had been. LRN representatives explained their plans. Three LRNs had two lay members, and others reported their plans to appoint at least two. Supplementary Resources has a different structure, with links to the MNDA and HDA.

PPI survey:

There was support for limiting the number of questions to about four, and going beyond a narrow "DeNDRoN-focus" to survey research-active GPs, Association of British Neurologists and Institute of Psychiatry, anonymously if wished, to establish a UK baseline for PPI. Roger Steel suggested a 'self-reflection' question about the process.

A subgroup can help to develop the questionnaire, and bring this back to the September meeting.

Evaluation:

The group debated about how one can judge the effectiveness of PPI. There was a consensus that we shouldn't try to evaluate PPI in DeNDRoN in any formal manner just yet, but over the coming year(s).

3 **DeNDRoN CSG/SIG patient/public membership recruitment**

3.1 Calling for lay members:

Terry McGrath reported on the recently-closed announcement calling for lay members to fill places in the Neuropathology & Brain Banking and Primary Care Clinical Study Groups and Methodology Special Interest Group, and thanked medical charities for their help with advertising these. Applicants will be selected according to the criteria outlined in the announcement.

Piers Kotting felt that the presence of three lay members on the Dementias CSG made a huge difference to the discussions.

3.2 LRN steering committees:

As mentioned above, recruitment of lay members on LRN steering committees was also underway in many LRNs using the 'Guidance on Recruitment of Patient/Public Members on DeNDRoN Local Research Network Steering Committees' as earlier approved by the PPI Working Group.

3.3 Two-way support:

Terry McGrath tabled his updated version of the document on 'Support For Lay Members'. This is an optional two-way process where a lay member links up with a professional member of the same DeNDRoN committee.

Terry will circulate to LRNs and Chairs of CSGs to consider.

4 Report back from the PPI Forum Development Day

4.1 Terry McGrath reported verbally on the day:

Terry reported that a key experience shared by many participants was feeling unclear how PPI can be effective operationally on DeNDRoN committees, and some people felt out of their depth. However, Terry reported that alongside this there was a strong consensus opposing any “demeaning” or “them-and-us” support methods for lay members.

Another repeated theme during the event was asking how patients, carers & medical charities can help LRNs with recruitment to studies.

4.2 The PPI Working Group felt that the day seemed a very encouraging step towards developing a collective PPI Forum mentality.

Recruitment through medical charities:

The issue (from the day) about study recruitment through (local) medical charities was discussed by the Working Group. The ethical and procedural obstacles around this are real and important, but it was felt that mechanisms to allow for this should be developed.

GP training:

Doug Mitchell felt that the call from the day for more GP training on raising research issues would be supported by many GPs.

Feedback on study outcomes:

The PPI Working Group felt that the call, for a prospective requirement that researchers systematically report the outcomes of DeNDRoN-supported research before they disappear elsewhere, was reasonable. This already happens in medical charity funded research, but should be spread. Avoiding pre-disclosure prior to publishing needs to be addressed, however, if this is developed in DeNDRoN.

5 Discussion on communication issues

5.1 Terry McGrath introduced the main challenges:

- how to bring lay members closer together,
- and how the steering group relates with the lay members/Forum

The goal is to strengthen the input into DeNDRoN of a collective patient and public perspective across diseases.

5.2 Although not all Forum members are on computer, nearly all current lay members on DeNDRoN local and national committees, and all of the current applicants, are internet users. Therefore, it was agreed that the use of internet and especially the Portal should be developed, as well as postal and telephone correspondence. It was recognised that we need to have more lay

members in place before a natural communications pattern evolves.

It was hoped that a series of regional Portal training sessions could be coordinated across all Topic Research Networks.

There was a request for a “live demonstration” of the Portal at the next meeting.

5.3 Terry is due to produce a PPI newsletter over the Summer.

6 Effectiveness of PPI

6.1 Patient Recruitment:

Due to shortage of time, there was only time to discuss one topic area from the ‘Priorities for PPI’ document. The Group chose to look at Patient Recruitment.

It was recognised that where Local Research Networks (LRNs) have problems and obstacles with particular studies, PPI should be strongly considered as part of the plans to overcome these. Local patients and carers could be invited to meet to discuss ‘failing’ studies and generate ideas.

The suggestion of general ‘awareness raising’ activity at a local level was discussed. Patients who’ve been in a study could be asked to talk about their experience (maybe as a recorded interview).

7 Developing lay summaries of research

7.1 Terry McGrath reported that soon, for new studies, short “lay” summaries will be required by the National Research Ethics Service for gaining ethical approval; the UKCRN will then be looking at how to link these into the UKCRN portfolio. Terry McGrath is due to attend a discussion which is related to this with members of the Alzheimer’s Society who are also lay members of the Dementias CSG.

Managing expectations around recruitment:

LRN staff present stressed the importance of managing expectations properly when publicising or promoting research.

8 Any other business

8.1 Belinda Cupid suggested we have name signs at future meetings, not just badges.

PPI WORKING GROUP ATTENDANCE RECORD

	Monday 25th February 2008	Wednesday 4th June 2008	Wednesday 8th October 2008
Steve Iliffe	✓	✓	due
Geoff Hanks	✓	APOLOGIES	APOLOGIES
U Hla Htay	✓	✓	APOLOGIES
Jean Waters	✓	✓	APOLOGIES
Helen Brewer, Huntington's Disease Association	✓	APOLOGIES	due
Belinda Cupid, Motor Neurone Disease Association	✓	✓	due
Bunia Gorelick, Parkinson's Disease Society	✓	✓	due
Susanne Sorensen, Alzheimer's Society	APOLOGIES	APOLOGIES	David Buglar due
North East LRN	✓ Vicki Hetherington	✓ Vicki Hetherington	Karen Morgan due
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	Lisa Curry due
DeNDRoN Supplementary Resources	APOLOGIES	Jenny Keylock	Jenny Keylock due
South Coast LRN	✓ Sandra Lawton	APOLOGIES	
North West LRN	✓ Angela Parker	APOLOGIES	Ruth Hunter due
Thames Valley LRN	✓ Rosemarie Streeton	APOLOGIES	Olivier Bazin due
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	Deborah Howcroft due
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	Juniper West due
Douglas Mitchell	✓	✓	due
Maryrose Tarpey, INVOLVE	✓	APOLOGIES	APOLOGIES
Marianne Miles, UK Clinical Research Network (UKCRN)	APOLOGIES	✓ Roger Steel representing UKCRN	Roger Steel due
Terry McGrath	✓	✓	due
			Guest: Shirley Nurock from the Dementias CSG

Ex officio attendees not recorded above include Martin Rossor, Piers Kotting, and Andrew Rutherford taking minutes.

DIARY DATES

DeNDRoN Annual Conference: Hilton, Newcastle-Gateshead: 14th October 2008

INVOLVE Annual Conference: Nottingham: 11th/12th November 2008

Next DeNDRoN PPI Working Group:
March 2nd, March 9th, or March 16th are all possible dates