

**Minutes of DeNDRoN PPI Working Group
1st November 2007**

PRESENT

- Dr. Steve Iliffe** - Chairperson, DeNDRoN Associate Director who has the PPI portfolio on the Executive
- Dr. Jean Waters** - Patient Representative
- U Hla Htay** - Patient Representative
- Professor Douglas Mitchell** - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals NHS Foundation Trust, who is MND Lead for DeNDRoN
- Dr. Belinda Cupid** - Research Manager, Motor Neurone Disease Association
- Dr. Marianne Miles** - Patient and Public Involvement Lead, UK Clinical Research Network
- Dr. Helen Brewer** - Care Advisor for Juvenile Huntington's Disease Huntington's Disease Association
- Maryrose Tarpey** - Public Involvement Adviser, INVOLVE
- Bunia Gorelick** - Research Grants Manager, Parkinson's Disease Society
- Dr. Susanne Sorensen** - Head of Research, Alzheimer's Society
- Terry McGrath** - PPI Coordinator, DeNDRoN

APOLOGIES

- Professor Geoff Hanks** - Patient Representative

MINUTES

ACTION

1 WELCOME AND INTRODUCTIONS

- 1.1 It was agreed that the new PPI Working Group should keep an attendance record.

2 NOTES SUMMARISING THE 'ROAD MAP GROUP' MEETING IN MARCH 2007

- 2.1 As a record of that discussion, the notes were accepted with no alterations. It was raised that with Terry McGrath's added comments, the end result felt over-ambitious.

2.2 Some discussion points were raised:

Generally agreed that the Working Group would benefit from more direct input from Local Research Networks into the group – see later Item 3 discussion.

The section about the PPI Forum needs a clearer focus describing its supportive and advisory role. Needs also to be clear whether 'professionals'

are included in the Forum.

2.3 Payment for time:

Marianne Miles updated the group on UKCRN discussions with Dept of Health around funding for payment for time.

U Hla Htay stated his strong agreement with the policy of not paying for time. Differing viewpoints were also discussed.

It was acknowledged that DeNDRoN will continue to adhere to a policy of not paying for time, as outlined by the notes of the Road Map Group meeting.

Terry McGrath commented that good quality public relationship management was as important as policy.

2.4 Confidentiality and conflict of interests:

The section of the Road Map Group meeting notes which covered guidance on this topic was expressly noted.

This contains the same general expectations on patient/public members on committees as for professionals about confidentiality and conflict of interests.

3 **DISCUSSION ON THE PROPOSAL AND REMIT FOR A PPI WORKING GROUP**

3.1 Terry McGrath introduced the remit in the context of recent/planned PPI activities around the country. He stressed the need to build up formal representation on key committees, together with a twin-track approach to ensure effective PPI in practical ways in DeNDRoN beyond formal representation.

3.2 The group supported the overall proposal to evolve into a PPI Working Group.

The Group felt that the proposed ends goals were good, but shorter-term objectives were needed. It was agreed that a one year plan should be drafted for the group. Terry McGrath to draft a short one year plan for the Group to discuss.

3.3 It was agreed that the PPI Working Group should meet three times a year, not four.

3.4 Strategic involvement:

Jean Waters felt that the PPI Working Group should include an aim to facilitate patient/public influence into wider clinical research funding discussions.

Steve Iliffe supported the suggestion for a core aim being to improve accrual to studies.

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3.5 Membership:

The proposed membership for the Working Group was supported with one amendment... As the group is quite large, it was agreed, after debate, not to include the 'two to three researchers' in the membership.

There was particular support for LRN/Supplementary Resource staff as members to be an effective link with the LRNs, in view of the desire for PPI to improve recruitment to studies.

4 **PROPOSED DATES FOR THREE PPI WORKING GROUP MEETINGS IN 2008**

4.1 An availability template, sent out earlier, was used to agree dates. Meetings will be:

Mon 25th February, Weds 4th June, and Weds 8th October.

ALL
to note
dates

5 **DISCUSSION OF DOCUMENT: 'AN ANALYSIS OF PRIORITY AREAS FOR PPI IN DeNDRoN'**

5.1 Proposed priorities and methods for each of the identified DeNDRoN processes were reviewed. Most of the recommended methods and levels of priority were agreed, but with amendments as below.

5.2 Assessment of commercial study research proposals and commercial study adoption

Jean Waters felt that PPI in commercial study adoption should be changed to a high, not low, priority for a number of reasons.

The Group acknowledged there were potential issues around confidentiality, the rapidity of the process, and the high level of scientific detail in commercial proposals. However, a high proportion of proposed studies could be commercial and this is a significant area which should not be overlooked for PPI.

One suggested way forward would be to have in place an identified "bank" of lay people who were each prepared in principle to be contacted at short notice by email, and had signed a generic confidentiality agreement. Maryrose Tarpey believed that the pharmaceutical industry may well find this very acceptable.

If some "bank" members were drawn from existing patient/public members on CSGs, they would already have knowledge of a particular proposed study.

Marianne Miles said that the UKCRN is aiming to develop recommendations to support PPI in commercial study adoption across all the Topic-Specific Research Networks.

In view of the time pressures and challenges involved, the PPI Working

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Group recommended developing a pilot to look at principles and practicalities

5.3 Study Feasibility: Determining the overall feasibility of DeNDRoN practically supporting a study

The PPI Working Group agreed to remove the line recommending use of Patient/Carer Advisory Panels.. Such panels could only really be used for PPI around feasibility, if they were disease-specific, and linked to CSGs.

5.4 Working Up Specific Proposals

For this, there was a recommendation from the Group to consider joint work with other charities or other Topic-specific Clinical Research Networks – the example of joint work around Stroke was given.

Again, CSGs may have an input to this work.

5.5 Study Set-up Processes: Practical setting up and delivery of study following the set protocol

Potential impact of PPI was currently agreed as per the document – i.e. MEDIUM. However, in future there is likely potential for this to become a HIGHER priority within LRNs.

5.6 Communications

The Group recommended linking together the four items in the document under 'Communications' (website, annual report, leaflets and other printed material, and planning of open events and conferences). These should collectively be seen as not low, but HIGH priority.

5.7 Interpretation Of Results And Dissemination

U Hla Htay felt that this was probably more the remit of the funders, as they would want to champion the study's results themselves.

The PPI Working Group therefore agreed that dissemination was not really a core DeNDRoN issue, and the priority was changed from high to LOW.

5.8 Terry McGrath will produce a final revised version incorporating all these changes.

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6 ANY OTHER BUSINESS

6.1 LRN /Medical Charity Links

It was suggested that there should be feedback to the next meeting about DeNDRoN's links with LRNs and medical charities.

DIARY DATES

2008 PPI Working Group meetings

- Finalised dates (to be in central London) are:
- Monday 25th February, Wednesday 4th June, Wednesday 8th October

DeNDRoN PPI Forum

- There is a PPI Forum being planned to bring together patient/public members involved in DeNDRoN, including PPI Working Group members who wish to attend, on:
- 19th/20th May 2008
- (Dinner on the 19th and accommodation will be provided)

DeNDRoN Annual Conference

- Set for 14th October 2008 in Hilton, Newcastle-Gateshead. Many people could be playing a role the day before - 13th - in various meetings (e.g. CSGs) and staying overnight in the Hotel.