
Minutes of DeNDRoN PPI Working Group 8th October 2008

PRESENT

Dr. Steve Iliffe - Chairperson, DeNDRoN Associate Director who has the PPI portfolio on the Executive

Dr. Helen Brewer - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association

Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association

Karen Morgan - from North East DeNDRoN

Lisa Curry - from North Thames DeNDRoN

Jenny Keylock - from DeNDRoN Supplementary Resources

Ruth Hunter - from North West DeNDRoN

Olivier Bazin - from Thames Valley DeNDRoN

Deborah Howcroft - from South West DeNDRoN

Juniper West - from East Anglia DeNDRoN

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

****Guest:* **Shirley Nurock** - from DeNDRoN Dementias CSG

APOLOGIES as received:

Professor Geoff Hanks - Patient Representative

U Hla Htay - Patient Representative

Dr. Jean Waters - Patient Representative

Bunia Gorelick - Research Grants Manager, Parkinson's Disease Society

David Buglar - (for Dr. Susanne Sorensen - Head of Research, Alzheimer's Society)

Sandra Lawton - from South Coast DeNDRoN

Maryrose Tarpey - Public Involvement Adviser, INVOLVE

Dr. Marianne Miles - PPI Lead, NIHR CRN ... but Roger Steel attended

****Ex officio:* **Piers Kotting** - Assistant Director, DeNDRoN

****Ex officio:* **Professor Martin Rossor** - Director, DeNDRoN

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1 Introductions and welcomes

2 Minutes from last PPI Working Group (04/06/2008)

2.1 Minutes were accepted with the following correction.

Under Sect. 2.5, It's 'Association of British Neurologists' (not 'Neurology')

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

2.2 Matters arising

PPI survey (Sect. 2.5): Terry still needs to email out the proposed wording/plan for the PPI survey.

DeNDRoN Annual Conference (14th Oct 08):

Terry outlined plans for the PPI Workshop on developing PPI 'tools' to help with pt accrual and establishing new research sites. The Working Group recommended changing 'tools' to 'processes' and explaining the goals of the session clearly, using real practical examples. Doug Mitchell suggested the overarching theme of the session is 'Recruitment by Patient Power'.

Terry also explained how a patient/carer focus group in Newcastle had helped to shape the day, e.g. workshop contents, quiet room.

3 External Review of DeNDRoN January 2009 – PPI aspects

3.1 The circulated draft of the PPI section of the External Review was discussed. Terry asked for comments to be sent to him (by 20th Oct) for incorporation.

Changes were suggested with reference to UKCRN & representation of structure and key relationships.

4 PPI Forum Development Day video

4.1 The DVD was watched by the group and discussed:

It was generally thought to be very good, but perhaps repetitive and overlong. There was felt to be insufficient MND and particularly HD input. Some sections and quotes were particularly useful, and there was support for making the DVD available for training, such as GPs and via UKCRN, INVOLVE and medical charities. Participants had signed permissions.

4.2 Terry handed out sets of DVD copies to LRN representatives present.

North Thames DeNDRoN had shown the DVD at a recent PPI event for interested lay people, where it was well received. Other LRNs were distributing it to some patient/carer contacts.

5 Updates from LRNs

5.1 There were updates from all LRNs present:

Recent PPI activities included focus group discussions about specific studies in East Anglia and South West (DOMINO and PD-MED), and a North Thames PPI open day. Other LRNs were developing databases on local patients' & carers' organisations, and individuals, and supporting their new Steering Committee lay members.

6 Discussion of PPI communication via DeNDRoN Portal

6.1 Terry McGrath demonstrated the NIHR Portal 'Patient/Public Pages', which lay members of CSGs have individual passwords to access.

https://portal.nihr.ac.uk/sites/dendron/ppi_new/Pages/default.aspx

Potential difficulties with using the technology were raised. The general sense was that we need to wait to see whether the Portal proves popular and useful as one of many avenues for generating ideas over time.

6.2 It was recommended that Portal access to lay people's contact details should be carefully controlled.

7 Developing lay summaries of research/Patient registers

7.1 The discussion opened with general comments on the topic, such as ethical considerations around 'advertising' studies, time and cost implications, and managing elevated expectations. Nonetheless there was a keenness to see things move forward.

Shirley Nurock outlined the work that she and Barbara Woodward-Carlton (both of whom are on the Dementias CSG and heavily involved in the Alzheimer's Society QRD network) have led on making information on key DeNDRoN trials easily accessible to patients and carers. With DeNDRoN's help, they were developing 'basic info' on particular studies which would tell people, in a few sentences, what they really needed in straightforward language, and - crucially - not solely internet-based.

Terry McGrath also outlined (but didn't circulate) Jean Waters work around a patient-driven register for those interested in participating in clinical research in MND. This was being looked at within the MND CSG.

7.2 The crucial role of linking with medical charities, nationally and locally, was raised.

- 7.3 It was acknowledged that the ploy of these particular approaches would differ in different diseases.

The discussion opened out to explore many of the detailed permutations of who and how research databases and patient databases could be developed. A central issue was who needs to be “at the other end of the phone” to handle specific enquiries.

The NIHR CRN is gradually improving its information – often called “Portfolio Two” – this time it’s personable.

8 Developing tools for effective PPI in DeNDRoN LRNs

- 8.1 There remained insufficient time to discuss this in any depth. It will be a constant theme in PPI. It was hoped that the PPI Session at Annual Conference could help with ideas for this.

9 Any other business

- 9.1 Date of next meeting was confirmed as March 9th 2009.

PPI WORKING GROUP ATTENDANCE RECORD

	25 th Feb 08	4 th Jun 08	8 th Oct 08	9 th Mar 09
Steve Iliffe	✓	✓	✓	<i>expected</i>
Geoff Hanks	✓	APOLS	APOLS	
U Hla Htay	✓	✓	APOLS	APOLS
Jean Waters	✓	✓	APOLS	<i>expected</i>
Helen Brewer, Huntington's Disease Association	✓	APOLS	✓	<i>expected</i>
Belinda Cupid, Motor Neurone Disease Association	✓	✓	✓	APOLS
Bunia Gorelick, Parkinson's Disease Society	✓	✓	APOLS	<i>expected</i>
Susanne Sorensen, Alzheimer's Society	APOLS	APOLS	DAVID BUGLAR APOLS	<i>David Buglar expected</i>
North East LRN	✓ Vicki Hetherington	✓ Vicki Hetherington	✓ Karen Morgan	<i>Daniel Herron & Margaret Piggott expected</i>
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	✓ Lisa Curry	<i>Lisa Curry expected</i>
DeNDRoN Supplementary Resources	APOLS	✓ Jenny Keylock	✓ Jenny Keylock	
South Coast LRN	✓ Sandra Lawton	APOLS	APOLS	<i>Yvette Lycett expected</i>
North West LRN	✓ Angela Parker	APOLS	✓ Ruth Hunter	<i>Clare Jones expected</i>
Thames Valley LRN	✓ Rosemarie Streeton	APOLS	✓ Olivier Bazin	<i>Olivier Bazin expected</i>
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	<i>Deborah Howcroft expected</i>
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	✓ Juniper West	<i>Juniper West expected</i>
Douglas Mitchell	✓	✓	✓	<i>expected</i>
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	<i>expected</i>
Marianne Miles, NIHR Clinical Research Network	APOLS	✓ Roger Steel	✓ Roger Steel	<i>Roger Steel expected</i>
Terry McGrath	✓	✓	✓	<i>expected</i>
Guests:			Shirley Nurock - Dementias CSG	Peter Webb - HD CSG

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

Next DeNDRoN PPI Working Group: I am suggesting any Wednesday in July 2009. Please could you think whether you might be free on these dates.

DeNDRoN Annual Conference: Likely to be 13th October 2008 on the South Coast.