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**Minutes of DeNDRoN PPI Working Group**

**9<sup>th</sup> March 2009**

Held at Methodist International Centre, London

PRESENT

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

**Professor Geoff Hanks** - Patient Representative

**Dr. Jean Waters** - Patient Representative

**Dr. Helen Santini** (*formerly Brewer*) - Care Advisor for Juvenile Huntington's Disease, Huntington's Disease Association

**David Buglar** - Quality Research in Dementia Liaison Officer (*in place of Dr. Susanne Sorensen - Head of Research*), Alzheimer's Society

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

**Olivier Bazin** - from Thames Valley DeNDRoN

**Lisa Curry** - from North Thames DeNDRoN

**Daniel Herron** - from North East DeNDRoN

**Deborah Howcroft** - from South West DeNDRoN

**Clare Jones** - from North West DeNDRoN

**Jenny Keylock** - from DeNDRoN Supplementary Resources

**Yvette Lycett** - from South Coast DeNDRoN

**Professor Douglas Mitchell** - Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN

**Margaret Piggott** - from North East DeNDRoN

**Roger Steel** - PPI Manager, NIHR CRN

**Maryrose Tarpey** - Public Involvement Adviser, INVOLVE

**Juniper West** - from East Anglia DeNDRoN

**Terry McGrath** - PPI Co-ordinator, DeNDRoN

Guests:

**Peter Webb** - from DeNDRoN HD CSG (part of meeting)

**Denise Wilson** - Study Development Manager, DeNDRoN

APOLOGIES

**U Hla Htay** - Patient Representative

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

**Dr. Marianne Miles** - PPI Lead, NIHR CRN

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

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

## **MINUTES of the DeNDRoN PPI Working Group held on 9th March 2009**

### **1 Introductions and welcomes**

### **2 Minutes from last PPI Working Group (08/10/2008)**

2.1 Minutes were accepted with one correction. "Section 6" is really Section 5.

#### **2.2 Matters arising**

Developing tools for effective PPI in DeNDRoN LRNs (Section 8): It was requested that this be put on the agenda for our next Working Group meeting.

### **3 External Review of DeNDRoN January 2009**

3.1 Terry summarised the (circulated) PPI pages in the DeNDRoN submission for the DoH Triennial Review. The review process was explained.

The informal feedback is that DeNDRoN PPI has been reviewed favourably. DeNDRoN now has to update strategies - including for PPI - following this review.

#### **3.2 PPI in study design**

The discussion turned to look at the desire that patients express for more PPI at the design stage and in writing protocols. It was acknowledged that most of DeNDRoN's studies 'arrive' with protocols already designed, but it was felt there must be scope for a greater PPI role in future research grant applications, including at LRN level, which could result in more effective research.

Denise Wilson, DeNDRoN's new Study Development Manager, said that 'closing the gap' between CSGs with LRNs should hopefully help to facilitate this. Maryrose Tarpey offered to send Terry McGrath a list of Research Design Service PPI Leads for dissemination.

The study adoption process was mentioned, with a remark that DeNDRoN seemed uncritical of commercial studies' proposed accrual targets at LRN level. One suggestion was that DeNDRoN Study Adoption Panels could point towards questions about capability & feasibility of each proposed study, which LRNs could use when quickly seeking some input from patients or carers.

### **4 Survey of cross-section of NHS clinical research-active community**

4.1 There was some questioning of the point of the survey. It had derived from an earlier hope to have some kind of baseline evaluation. One suggestion

was that it might produce an anecdotal group of responses, but these could at least provide some useful individual quotes, insights and perspectives.

The group recommended that if the survey happens, it should use an online electronic survey tool, with an option for respondents to be anonymous. Terry agreed to reword and slightly expand it, then either circulate it before the next meeting or bring it to our next meeting. It was recommended to look at the earlier UKCRN CC work in evaluation.

- 4.2 There were a number of additions or amendments recommended to the circulated draft. Alterations were suggested to the target audience of 'research initiators' and leaders in dementia & neurodegenerative disease NHS clinical research. Suggestions included:
- Association of British Neurologists
  - Institute of Psychiatry
  - the Old Age Psychiatry section of the Royal College of Physicians
  - A cross-section of research-active GPs identified via the Chairs of each DeNDRoN CSG, focussing on research initiators and leading research-active NHS clinicians/teams
  - The RCP Faculty of the Psychiatry of Old Age
  - Royal College of Nursing
  - British Geriatrics Society
  - Royal College of Physicians
  - College of Occupational Therapists
  - Chartered Society of Physiotherapy,
  - and to consider other professions allied to medicine

Debbie Howcroft (South West DeNDRoN) volunteered to help with a pilot to take this forward.

## **5 Obtaining feedback from research participants**

### **5.1 Feedback suggestion paper from North Thames DeNDRoN**

The paper 'Patient and Public Involvement – Suggestion from North Thames DeNDRoN Steering Committee' was submitted for discussion on behalf of North Thames DeNDRoN.

Lisa Curry introduced the topic. The paper raised ideas for obtaining feedback from DeNDRoN research participants on their experiences of research. Issues for discussion included: How can researchers collect feedback systematically? What role could DeNDRoN play in analysing feedback? Could a standard set of questions be developed?

- 5.2 The PPI Working Group agreed that the principle was very good, and might prove beneficial for accrual to studies where DeNDRoN is having difficulty recruiting participants. Feedback could also help more generally to improve the way studies meet patient interests.

However, there were some caveats:

- This would take some extra resource in order to be carried out properly.
- Any formalized process for gathering feedback would need to be robust and agreed by the ethics committee.
- DeNDRoN doesn't fund research itself, and collating and analysing feedback would not be done by the researchers themselves.

The general opinion was that, for this to happen, it would need to be part of the DeNDRoN auditing and monitoring role, not research.

Terry McGrath mentioned that, in some LRNs, general patient & carer discussion groups had examined specific studies (primarily DOMINO), but did not include research subjects themselves. One suggestion was in-depth interviews with a small number of participants.

Roger Steel recommended looking at work done by National Centre for Social Research (NatCen) on research ethics. See [www.natcen.ac.uk](http://www.natcen.ac.uk)

- 5.3 It was recognised that there were certainly examples within DeNDRoN of studies where recruitment is slow, and the general idea merited further consideration.

It was suggested that Lisa Curry draft some thoughts on this to go to DeNDRoN Executive.

## **6 Offering payment for time to CSG lay members**

- 6.1 Terry summarised the circulated briefing entitled 'Introducing Voluntary Offers of Payment for Time for formal national DeNDRoN Lay Members, e.g. of Clinical Studies Groups: Some background information'.

He explained that the National Institute for Health Research (NIHR) has made available additional funds to the DeNDRoN Co-ordinating Centre for DeNDRoN national-level formal lay involvement (chiefly CSGs), to support payment for time.

The PPI Working Group members recognised its optional nature as part of a wider DH move away from dependence on volunteers, but welcomed the important fact that DeNDRoN will continue, in addition, to foster a range of less formal unpaid patient and carer involvement activities at the national level.

Terry McGrath made clear that the extra funding is for national-level activity, not LRNs.

- 6.2 It was agreed that the change has to be explained properly to each individual lay member, and across DeNDRoN, stressing the entirely voluntary nature of any payment. Some key messages need to be:
- Agreeing to any offers of payment will be entirely optional.
  - DeNDRoN needs to make available some information around tax and benefits implications.
  - A whole range of PPI activities, such as attending discussion groups and focus groups, informal working groups, and all LRN involvement activities, will remain unpaid.

A number of questions were addressed. For example, it should be construed as an expense or fee rather than implying any employment relationship, and it cannot be back-dated.

## **7 This afternoon's DeNDRoN meeting (i.e. 9<sup>th</sup> March 2009)**

- 7.1 The proposed agenda for the DeNDRoN national lay members' meeting happening that afternoon was welcomed. The afternoon should critically review PPI in DeNDRoN to date, and recommend ways for PPI to have an impact in DeNDRoN's future activities.

Two areas where PPI Working Group members hoped the afternoon's discussion would focus on were DeNDRoN's core work on assessing LRN study feasibility and improving accrual rates to DeNDRoN studies.

## **8 Any other business**

Mr Peter Webb – a lay member from the Huntington's Disease CSG – was welcomed. It is proposed he becomes a member at the next meeting.

### PPI Working Group Attendance Record (since start of 2008)

	25 <sup>th</sup> Feb 08	4 <sup>th</sup> Jun 08	8 <sup>th</sup> Oct 08	9 <sup>th</sup> Mar 09	29 <sup>th</sup> July 09
Steve Iliffe	✓	✓	✓	✓	
Geoff Hanks	✓	APOLS	APOLS	✓	
U Hla Htay	✓	✓	APOLS	APOLS	
Jean Waters	✓	✓	APOLS	✓	
Peter Webb	<i>*It is proposed that Peter Webb joins as a new member at 29/07 meeting*</i>				
Helen Santini, (formerly Brewer), Huntington's Disease Association	✓	APOLS	✓	✓	APOLS
Belinda Cupid, Motor Neurone Disease Association	✓	✓	✓	APOLS	
Bunia Gorelick, Parkinson's Disease Society	✓	✓	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	
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	✓ Lisa Curry	✓ Lisa Curry	
DeNDRoN Supplementary Resources	APOLS	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	
South Coast LRN	✓ Sandra Lawton	APOLS	APOLS	✓ Yvette Lycett	
North West LRN	✓ Angela Parker	APOLS	✓ Ruth Hunter	✓ Clare Jones	
Thames Valley LRN	✓ Rosemarie Streeton	APOLS	✓ Olivier Bazin	✓ Olivier Bazin	
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	APOLS
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	✓ Juniper West	✓ Juniper West	
Douglas Mitchell	✓	✓	✓	✓	APOLS
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	✓	
Marianne Miles, NIHR Clinical Research Network	APOLS	✓ Roger Steel	✓ Roger Steel	✓ Roger Steel	APOLS
Roger Steel, NIHR CRN					APOLS
Terry McGrath	✓	✓	✓	✓	
<b>Guests:</b>			✓ Shirley Nurock - Dementias CSG	✓ Peter Webb - HD CSG ✓ Denise Wilson - DeNDRoN	

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