
**Minutes of DeNDRoN PPI Working Group
23rd November 2010**

Held at DeNDRoN Coordinating Centre office in London.

PRESENT

Dr. Jean Waters - Patient Representative: chairing as Professor Douglas Mitchell was unable to attend due to illness
Abigail Wright - South West DeNDRoN LRN
Adam Smith - DeNDRoN Project Manager
Dr. Belinda Cupid - Research Manager, Motor Neurone Disease Association
Bunia Gorelick - Research Grants Manager, Parkinson's UK
Caroline Struthers - Project Manager, Cochrane-NHS Engagement Project
Graham Thorp - Lay member, DeNDRoN Neuropathology & Brain Banking CSG
Jenny De Souza - DeNDRoN Supplementary Resources
Joanne Cross - Thames Valley LRN
June Pearson - North East LRN
Dr. Margaret Piggott - North East LRN
Maryrose Tarpey - INVOLVE
Olivier Bazin - Thames Valley LRN
Peter Gudge - Systems Administrator, DeNDRoN
Peter Webb - Patient Representative
Piers Kotting (*for part of meeting*) - Assistant Director, DeNDRoN
Ruth Chandler - Staff of Sussex NHS Partnership as a representative on behalf of South Coast DeNDRoN LRN steering committee
Sheila Parker - East Anglia LRN
Dr. Steve Iliffe - Associate Director, DeNDRoN – has the PPI portfolio on the DeNDRoN Executive
Terry McGrath - PPI Co-ordinator, DeNDRoN
U Hla Htay - Patient Representative

APOLOGIES

Professor Douglas Mitchell - Chairperson, and Assoc. Med. Dir. R&D, Lancashire Teaching Hospitals, who is MND Lead for DeNDRoN
Professor Geoff Hanks - Patient Representative
Dr. Helen Santini - Care Advisor for Juvenile Huntington's Disease at the Huntington's Disease Association
Dr. Susanne Sorensen - Head of Research, Alzheimer's Society
North West LRN and **North Thames LRN** representatives (*Note: As there is formally only one staff or lay representative from each LRN, apologies are only noted if no-one attends for an LRN*)
Roger Steel - PPI Manager, NIHR CRN
Dr. Marianne Miles - PPI Lead, NIHR CRN
Also apologies from ex-officio invitee: **Professor Martin Rossor**

MINUTES – 23rd November 2010

1 Introductions and welcomes

Jean Waters, chairing the meeting, welcomed everyone. All present wished to send our very best wishes to Professor Douglas Mitchell.

2 Minutes from last PPI Working Group (13th July 2010)

Previous minutes were agreed as correct.

Matters arising

The acronyms on page 5 need explanation:

- 'CLAHRC' means an NIHR Collaboration for Leadership in Applied Health Research and Care - a partnership between a University and the surrounding NHS organisations to improve patient outcomes through applied health research.
- 'BRC/U' means Biomedical Research Centres and Units – these are based within NHS and University partnerships to undertake translational clinical research and translate fundamental biomedical research into clinical research into technologies, techniques and treatments for improving health.

Section 5.2: It was asked what has happened re training plans. This is an agenda item today, and it was noted that training will also be a topic in the planned PPI issues consultation.

3 Impact & Effectiveness of PPI within DeNDRoN

3.1 Terry McGrath introduced a discussion about how we can work better with the PPI Forum – i.e. lay people nationally and locally. These are mainly dementia and PD related contacts, but unless they have become active in an LRN or CSG, many have not been engaged with in a systematic way.

It was recognised that DeNDRoN's Writing Groups, now developing new study ideas, are starting to require more systematic PPI.

Consulting on how to make PPI work in DeNDRoN

DeNDRoN's new five year plan will need to be the focus for PPI activities. There needs to be a consultation around the practicalities of embedding PPI in delivering the plan.

3.2 Terry presented this chart looking at:

1. DeNDRoN processes where lay people (PPI Forum, etc) insist PPI must have high impact
2. DeNDRoN processes where **DeNDRoN's overall strategy and five year plan implies a high relevance of PPI input.**

The **HIGH/HIGH** box identifies those processes which are highly important to lay people and to DeNDRoN strategy.

		Where DeNDRoN's strategy implies a high relevance of PPI input	
Where lay people insist PPI must have high impact		LOW OR MEDIUM	HIGH
	LOW OR MEDIUM	Operational and performance management Capability Study set-up Staff recruitment Commercial adoption Feasibility assessment Strategic management	
	HIGH	Non-commercial adoption Funder engagement Printed communications	Gaps in research Local ideas generation Writing Groups Recruitment to studies Training Public Relations

3.3 Consultation

It is proposed that these **HIGH/HIGH** elements be where DeNDRoN's PPI work be focussed. How we go about that is what the consultation is about.

Steve Iliffe stressed that the **highest priority element in DeNDRoN's strategy is study recruitment**, so consulting on how to include PPI around this is crucial.

This five year plan also coincides with the strong PPI Forum demand for **closer work with medical charities/patient representative organisations**. DeNDRoN's plan suggests looking at **possible new staffing arrangements involving the medical charities directly** to see if that could enhance collaboration with medical charities for improved patient outcomes. This will form another element of consultation work.

3.4 How can we link lay people into delivering PPI for the high priority goals?

It was felt that patient/carer contacts of the DeNDRoN LRNs are well placed to help with avenues for recruitment to studies.

However, some issues were raised which need addressing:

- Each LRN has a different number of patient/carer contacts on their LRN lay panels – some very few – some quite a lot.
- Most LRNs cover a huge geographical area, so travel and other logistics will affect PPI feasibility.
- Logistics of PPI for the relatively lower incidence disease areas could be particularly “problematic”.

Terry raised a real life example of a PhD student requesting assistance for an MND study in development which may well not ever be part of the NIHR/DeNDRoN portfolio. This highlighted a key question of where the boundary lies between what study development PPI to actively support and what not to support.

- 3.5 In discussion, the consensus was that, if the PPI Forum members have called for PPI in study development, in training, and in “PR”, these should be the DeNDRoN PPI focus, such as considering a national “Get Involved In Research” day.

It was acknowledged that specific “tailoring” of lay experience and expertise for particular research issues and topics will be a challenge.

3.6 CSG lay member report

Graham Thorp (Lay Member of the Neuropathology & Brain Banking Clinical Studies Group) gave some lay perspectives on the expectations, the reality of membership, achievements, disappointments, surprises, and several frustrations experienced of being part of that CSG. It also included comments by the CSG’s other lay members. Their comments included various misgivings about the point and “clout” of the CSG as a whole, and it assessed the worth of a sub-group initiated by the lay members about funding for autopsy work. The report can be seen alongside these minutes.

The PPI Working Group congratulated Graham on his work and report, and felt it should be noted that the lay members’ PPI input into the sub-group on funding for autopsy work was substantial and important.

We discussed what additional help DeNDRoN might offer to all CSGs, and it was recommended that Terry send INVOLVE’s ‘PPI in Research Groups: Guidance for chairs’ to all DeNDRoN Chairs (maybe already done so).

3.7 Writing Groups

Terry outlined how DeNDRoN’s various study development taskforces and Writing Groups are working. Information and reports are now starting to appear on the DeNDRoN website.

The main issue for PPI is that there is likely to be a big increase in requirement for lay involvement in lots of areas in the near future. The PPI input to date has been in dementia study development concerning assistive technologies, end of life care, and care homes. A step change in PPI input may be needed, with more dementia PPI and work around PD, MND and HD-related Writing Groups.

Terry McGrath reported having recently written the PPI section for one of the first DeNDRoN Writing Groups to get to the stage of programme grant application.

Various members of the PPI Working Group are on CSGs, and discussed their insights on this topic. Peter Webb in the HD CSG had some similar experiences to Graham's. He stressed the value and importance of the lay members' role, representing their individual lay people's insights and experiences; it is also important to remember that being on a CSG is a very valuable learning experience for lay people. Peter mentioned his contribution to the End Of Life Writing Group activity and that a particularly crucial aspect was the cross-disease input.

4 Training

Terry McGrath reiterated the key DeNDRoN training priorities for lay people, already identified by the PPI Forum and this Group's last meeting.

Ruth Chandler (Sussex Partnership Service User & Carer Co-ordinator) introduced a draft example of what a training template for DeNDRoN could look like.

The draft example can be seen alongside these minutes.

4.1 The Group felt Ruth's draft example of a session outline and teaching material was excellent.

Ruth talked through the rationale behind the training example, which is to enable people to look at how they can use their experience. Ruth would be happy to write training session materials, but needs a mandate to clarify the learning pathways required.

It was noted that this approach would be especially relevant to cross-disease Writing Groups, such as End Of Life, where lay people from different perspectives work together.

4.2 The key consultation questions:

- **How should training be structured and funded to meet DeNDRoN and NIHR objectives?**
- **Who is best placed to deliver 'off the shelf' training modules and other elements of this training, e.g. DeNDRoN, NIHR networks/organisations in general, plus how medical charities and other training expertise might help in delivering DeNDRoN-specific training?**

The PPI Working Group members wanted to stress collaboration rather than outsourcing.

The Group also thought the simplest approach was to develop DeNDRoN-specific training. Several examples of existing generic training across the UK were mentioned, but often very over-subscribed, and in "pockets" far away.

Relevant and local modules were preferable, with emphasis on training around participation rather than specifics of disease areas. The recent INVOLVE

conference included a very positive session on research networks pooling resources locally.

Maryrose added that informal support mentoring was particularly valuable. Terry felt that in DeNDRoN it had proved difficult to get much mentoring going, but some two-way support mechanisms had been taken up by some 'professional' and lay people on some DeNDRoN CSGs.

- 4.3 **It was agreed that Ruth's training example should form the basis of some specific in place for PPI Forum members.** In particular, Writing Group personnel should be encouraged to go through the exercise of session two (+ maybe session one) of Ruth's training example. PPI reps and researchers would learn from this. TM should coordinate some training and evaluation.

5 PPI plans in DeNDRoN and the NIHR PPI Way Forward

Piers Kotting, DeNDRoN Assistant Director, spoke about DeNDRoN's PPI planning in relation to the NIHR PPI Way Forward and to DeNDRoN's five-year plan. Below are two key slides. The full presentation is viewable for those with access to the DeNDRoN PPI Working Group meeting pages on the NIHR Portal.

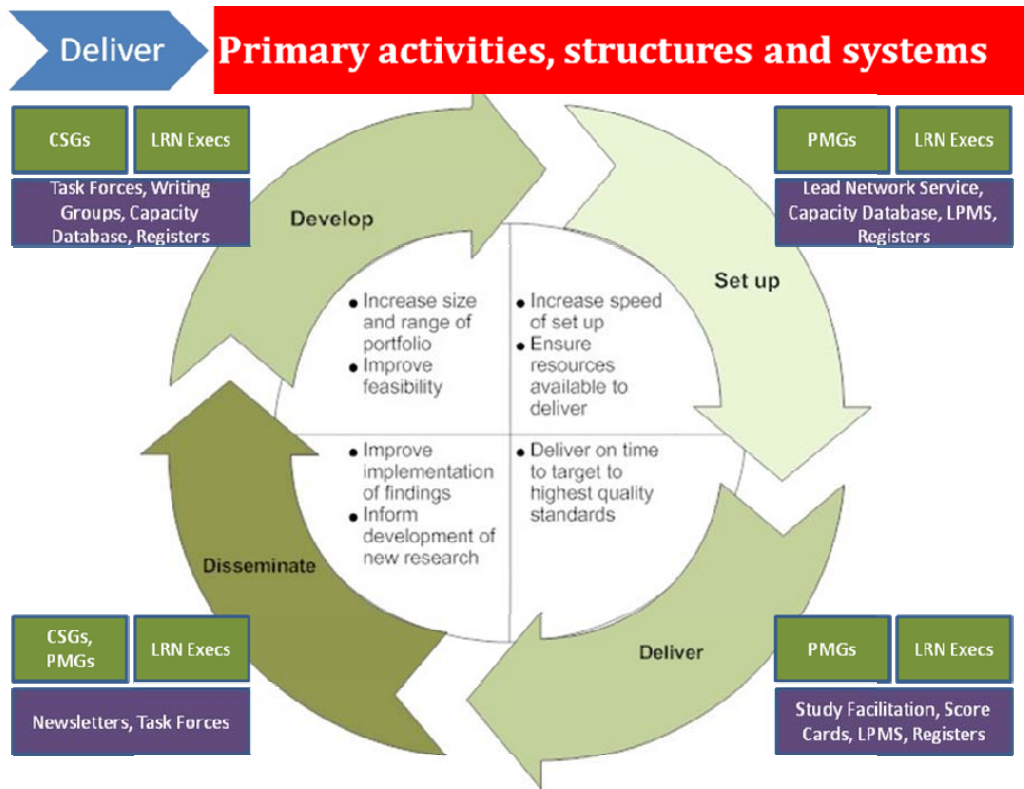
Key concepts to consider are **1) engagement with stakeholders and 2) delivery of outcomes.**

1) How best to engage with stakeholders?

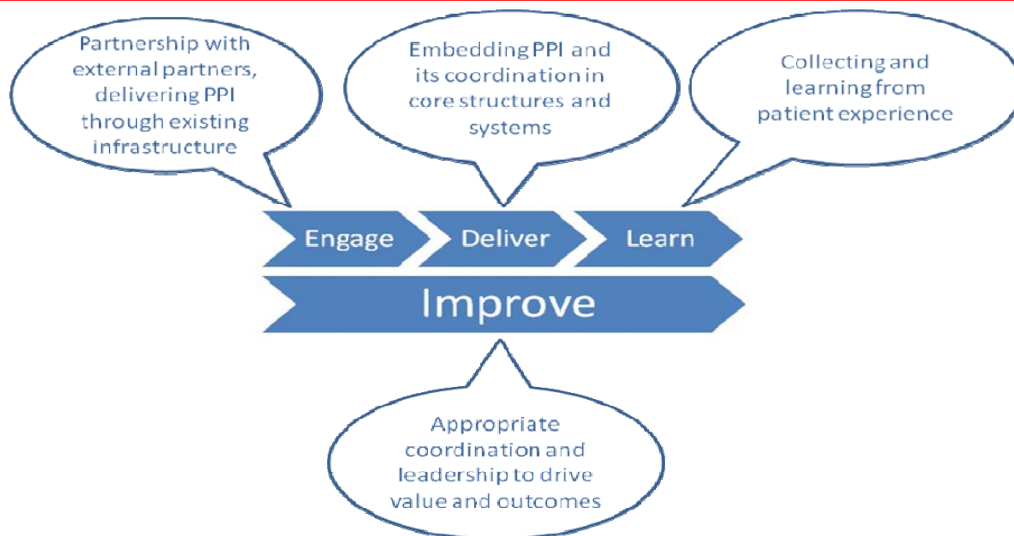
These include 58 Mental Health Trusts, 176 Acute Trusts, 1000s of GPs, and of course patients, carers, and the full range medical charities and patient representative organisations. We looked at the figures for the membership and branch structures of the main DeNDRoN-relevant medical charities.

2) How can PPI improve DeNDRoN's outcomes?

Embedding PPI is needed in all DeNDRoN processes from portfolio management to dissemination, but the key question is where PPI efforts, and funding for it, should be directed for the best outcomes.



Summary



5.1 How do we go forward?

Take bottom right hand corner, and that is agreed focus of PPI forum, and how do we achieve impact? Need action plan on what to do, when to start.

Put out first version on if focuses are right and how could be worked through, then put out second more concrete version with who does what and funding.

We need to be able to identify how PPI as a whole should be structured and funded. NIHR PPI Way Forward all embracing, but lacks specificity – we need to add this.

The consultation is about how we put into practice, fund particular pieces of work to include PPI, and **who** does it, e.g. medical charities, ethics, RDS, BRCs, other stakeholders.

RC: use medical charities, but should not lose centre around DENDRON. It was felt that embedding PPI in DeNDRoN needs someone to coordinate all the way through, and drive it through.

- 5.2 On the particular topic of collecting and learning from patient experience, Ruth mentioned have a service led audit of clinical trials – using DH guidelines – used with patients when a trial had finished. Ruth has the questionnaire if needed. Jenny De Souza mentioned that, from patients and carers who had chosen NOT to take part in HD research, a lot had been learned about improving recruitment. Terry mentioned that DeNDRoN executive had looked previously at similar ideas from North Thames DeNDRoN, and recommended this should be part of the governance process rather than formal research into service evaluation.

6 A unique role for lay volunteers

Go to: <http://www.medicine.ox.ac.uk/alois> for full details

Caroline Struthers (Cochrane-NHS Engagement Project Manager) discussed the role of lay volunteers in ALOIS, a comprehensive register of dementia studies, and how lay people, especially carers of people with dementia, might be able to get involved.

- 6.1 Put advert on portal/website – anyone interested – will pay expenses for travel.
- 6.2 Will it be advertised/promoted outside Thames Valley? They'll concentrate on Thames Valley for workshop in Oxford, but in future will not limit it to that area.

7 Any other business

- 7.1 Peter Webb: One way for easy low-cost training is having a proper handover, having a lay member leaving a CSG handing over to the new one/could act as a mentor. Chairs of CSGs have a role in decisions around this.

It was noted that National Cancer Research Network has done work on an exit questionnaire.

8 Date of next meeting

- 8.1 ***** The agreed date for the next meeting is 30th March 2011 *****

PPI Working Group Attendance Record

	25 th Feb 2008	4 th June 2008	8 th Oct 2008	9 th March 2009	29 th July 2009	23 rd Nov 2009	15 th March 2010	13 th July 2010	23 rd Nov 2010
Steve Iliffe	✓	✓	✓	✓	✓	✓	✓	✓	✓
Douglas Mitchell	✓	✓	✓	✓	APOLS	✓	APOLS	✓	APOLS
Geoff Hanks	✓	APOLS	APOLS	✓	✓	APOLS	✓	APOLS	APOLS
U Hla Htay	✓	✓	APOLS	APOLS	✓	APOLS	✓	✓	✓
Jean Waters	✓	✓	APOLS	✓	✓	✓	✓	✓	✓
Peter Webb	Peter joined in 2009			✓	✓	APOLS	✓	✓	✓
Helen Santini, Huntington's Disease Association	✓	APOLS	✓	✓	APOLS	APOLS	APOLS	APOLS	APOLS
Belinda Cupid, Motor Neurone Disease Association	✓	✓	✓	APOLS	✓	APOLS	✓	✓	✓
Bunia Gorelick, Parkinson's Disease Society	✓	✓	APOLS	✓	✓	APOLS	✓	APOLS	✓
Susanne Sorensen, Alzheimer's Society	APOLS	APOLS	David Buglar APOLS	✓ David Buglar	✓	✓	✓	APOLS	APOLS
North East LRN	✓ Vicki Hetherington	✓ Vicki Hetherington	✓ Karen Morgan	✓ Daniel Herron & Margaret Piggott	✓ Margaret Piggott	✓ Margaret Piggott	✓ Margaret Piggott	✓ Margaret Piggott	✓ June Pearson & Margaret Piggott
North Thames LRN	✓ Katy Judd	✓ Catherine O'Keeffe	✓ Lisa Curry	✓ Lisa Curry	✓ Lisa Curry	✓ Katy Judd	✓ Katy Judd & Lisa Curry	✓ Katy Judd & Ruth Hudson	APOLS
DeNDroN Supplementary Resources	APOLS	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny Keylock	✓ Jenny De Souza	APOLS	APOLS	✓ Jenny De Souza
South Coast LRN	✓ Sandra Lawton	APOLS	APOLS	✓ Yvette Lycett	✓ Yvette Lycett	✓ Yvette Lycett	APOLS	✓ Ruth Chandler	✓ Ruth Chandler
North West LRN	✓ Angela Parker	APOLS	✓ Ruth Hunter	✓ Clare Jones	✓ Clare Jones	APOLS	✓ Clare Jones	✓ Clare Jones	APOLS
Thames Valley LRN	✓ Rosemarie Streeton	APOLS	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	✓ Olivier Bazin	✓ Caroline Cox & Anne Silk	✓ Joanne Cross & Olivier Bazin
South West LRN	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	✓ Deborah Howcroft	APOLS	✓ Abigail Wright	✓ Abigail Wright	✓ Abigail Wright	✓ Abigail Wright
East Anglia LRN	✓ Jennifer Wilson	✓ Caroline Lindsay	✓ Juniper West	✓ Juniper West	✓ Juniper West	APOLS	✓ Karen Smith	APOLS	✓ Sheila Parker
Maryrose Tarpey, INVOLVE	✓	APOLS	APOLS	✓	✓	APOLS	APOLS	✓	✓
Marianne Miles, NIHR Clinical Research Network	APOLS	✓ Roger Steel	✓ Roger Steel	✓ Roger Steel	APOLS	✓ Roger Steel	✓ Roger Steel	APOLS	APOLS
Roger Steel, NIHR CRN					APOLS				
Terry McGrath	✓	✓	✓	✓	✓	✓	✓	✓	✓
<p>... Ex-officio attendees ... plus guests ... Ex officio attendees may include Martin Rossor and Piers Kotting</p>			Shirley Nurock - Dementias CSG	Denise Wilson - DeNDroN	Piers Kotting	Martin Rossor & Piers Kotting	Martin Rossor (morning)	(Peter Gudge taking notes)	Graham Thorp, Adam Smith, Piers Kotting, & Caroline Struthers, (plus Peter Gudge taking notes)