

One-year remit of the DeNDRoN PPI Working Group: up to April 2009

Introduction

As a part of seeking to develop and improve clinical research throughout the UK, and, from the patients' perspective, increase the relevance and acceptability of the research undertaken, DeNDRoN wants an increase in the direct involvement of those affected by these conditions to inform and help guide its decisions.

This draft document contains a one-year plan for DeNDRoN patient and public involvement (PPI) up to April 2009, and will be discussed by the May 2008 DeNDRoN PPI Working Group.

This can be read in conjunction with the longer term 'Remit of the DeNDRoN PPI Working Group' document as discussed/amended by the Group back in November 2007, which contains full details concerning principles, strategic involvement, responsibilities, structure and accountability, and membership.

Membership

A PPI Working Group has been established to oversee and advise on active patient and public involvement.

This is comprised of:

- Chairperson, who will initially be the DeNDRoN Associate Director who has the PPI portfolio on the Executive;
- Up to four patients, carers, or from the wider public, affected by dementias and neurodegenerative diseases with some experience of being actively involved in research;
- One professional representative from each of the seven Local Research Networks and from Supplementary Resources; and NEURODEM Cymru as appropriate;
- Representatives of appropriate partner and other relevant organisations, e.g. 'Involve', Alzheimer's Society, Parkinson's Disease Society, Motor Neurone Disease Association, Huntington's Disease Association;
- The DeNDRoN PPI Coordinator;
- DeNDRoN Directors or named nominees may also attend ex officio. This includes the Assistant Director and the MND Lead for DeNDRoN.

The PPI Working Group will be supported by the DeNDRoN PPI Coordinator

Responsibilities of the Group

The Groups will be responsible to the DeNDRoN Executive and Operational Steering Group, and have an advisory role to support the Clinical Study Groups, Special Interest Groups, and Study Adoption processes, Local Research Networks, Supplementary Resources, and also Devolved Nations work when appropriate.

The Group will:

- Be a resource for guidance on how the DeNDRoN Coordinating Centre should develop the PPI programme, including training and support, recruitment of patient and public members to Network activities locally and nationally, and monitor the progress and effectiveness of patient and public involvement across Network activities.
- Advise on the development of overall DeNDRoN policies and guidance in respect of improving clinical research for the benefits of, and taking account of, the people affected by these conditions.
- To advise and provide support for the DeNDRoN Local Research Networks, Adoption Panels and Clinical Studies Groups on actively involving patients, carers and the public in clinical research activities.
- To report with recommended actions to the DeNDRoN Operational Steering Group and Executive.

2008 targets

In 2008, the PPI Working Group will support the following targets:

June 2008

- DeNDRoN needs to have formal patient/public representation in place on all targeted LRN and national DeNDRoN committees – as already identified in the Priorities document by the DeNDRoN Working Group.
- There should be PPI on all those committees, with a minimum of two lay members on the committees. The timing and venues of committee meetings should take into account the needs and preferences of lay members.
- DeNDRoN needs to establish an initial opportunity for patient/public representatives to meet together as a PPI Forum, which will also include other patient/public individuals who are active in DeNDRoN PPI in other ways.

By September 2008

- To develop a survey of attitudes to PPI across DeNDRoN.
- A full patient and public involvement strategy should be developed and agreed by the Working Group.
- The impact of the programme should be regularly reviewed, and should evolve as the Network's activities progress.

By December 2008

- To develop a practical toolkit of concrete PPI methods for active patient/carer involvement of people affected by these conditions.

- To have an initial evaluation or 360° appraisal of the impact of PPI so far within DeNDRoN, in terms of supporting the achievement of DeNDRoN's aims, with particular emphasis on formal patient/public representation on key committees, and on the early impact of PPI into accrual of patients to DeNDRoN's portfolio of studies.

By April 2009

- The PPI Working Group will support a scoping exercise to examine what role DeNDRoN could have, and in particular any possibilities for input by the PPI Working Group, with respect to broader UK discussions and decisions on the funding of NHS Clinical Research.

Draft as amended for consideration in May 2008 by PPI Working Group