

## **Patient & Public Involvement Programme: Start-up Strategy**

Our Patient and Public Involvement strategy will play a pivotal role in ensuring that the Dementias & Neurodegenerative Diseases Network (DeNDRoN) supports clinical research that is of the highest quality, and is of direct relevance to people affected by these diseases, including dementia, Parkinson's disease, motor neurone disease and Huntington's disease. The adoption of clinical studies to the Network will be done in partnership, between people affected by these conditions, and the clinical researchers and healthcare professionals working in this field. Both groups will contribute to the prioritisation, design, conduct, reporting and dissemination of research.

### **1. Definition of terms used**

'Patient and Public Involvement' (PPI) is taken to mean involving all members of the public affected by the diseases represented by the DeNDRoN. This includes people with these diseases, their carers, family and friends, and members of the public who have an interest in the disease. A 'carer' is a relative, friend, neighbour or partner who, without payment, provides (or intends to provide, or used to provide) care to another person on a regular basis. Throughout this document PPI will be used to describe the involvement of this broad range of people. The term 'people affected by these conditions' is used to refer to people affected by the disease areas covered by the DeNDRoN (particularly the dementias, and Parkinson's, Huntington's and motor neurone diseases). 'Lay members' is used to refer to people affected by these conditions who are members of a DeNDRoN committee acting in a non-professional capacity.

### **2. Aims**

- To ensure that the views and perspectives of people affected by these conditions inform the DeNDRoN strategy.
- To develop systems to inform and actively involve people affected by these conditions in clinical research at all stages of the research process both locally and nationally.

### **3. Principles**

- The views and perspectives of people affected by these conditions should inform the DeNDRoN strategy.
- There should be an open and transparent system of PPI in all DeNDRoN activities.
- Active involvement should be at all stages and all levels of the research process.
- The role of people affected by these conditions within the different components of the DeNDRoN should be clearly defined.
- There should be PPI on all key national and local DeNDRoN committees. There should be a minimum of two lay members on these committees.
- There should be PPI in all DeNDRoN activities including production of information (newsletter, website etc.); and attendance at conferences and events.

- The timing and venues of committee meetings should take into account the needs and preferences of lay members.
- Training, mentoring and support should be provided for people affected by these conditions and researchers, in relation to best practice for PPI, as well as other identified needs.
- Information about the DeNDRoN should be accessible to patients, carers and the public.
- Duplication and fragmentation with other PPI initiatives and other organisations should be avoided. (e.g. the UKCRN, INVOLVE)
- The impact of the programme should be regularly reviewed, and should evolve as the Network's activities progress.

#### **4. Objectives**

- To form a working party of experts (PPI Road Map Group – see Section 5) who have experience and expertise in involving people affected by these conditions in research and service development; people affected by these conditions with some experience of active involvement in research; representatives of dementia, Parkinson's, MND and Huntington's medical research charities; and representatives of the DeNDRoN Coordinating Centre. The PPI Road Map Group will lead/advise on the PPI programme and its progress.
- To establish and support a group of people affected by these conditions (Patient and Public Involvement Forum – see Section 6) who will advise and inform the DeNDRoN Directors, Operational Steering Group, Clinical Studies Groups and Study Adoption Panel on neurodegenerative disease research priorities from the perspective of those 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 develop best practice guidelines about different methods and levels of active involvement of people affected by these conditions in clinical research.
- To be a central resource to provide patient and carer input into the development of new research studies and lay peer review of research proposals and papers.
- To organise in partnership with members of the Patient and Public Involvement Forum annual meetings in DeNDRoN Local Research Networks to inform patients, carers and the public about recent developments in neurodegenerative diseases research and Network activities (new and ongoing studies).
- To develop communication strategies to inform people affected by these conditions about neurodegenerative diseases research and DeNDRoN activities via appropriate media e.g. DeNDRoN website, newsletter, events.

#### **4. Establishing a PPI Road Map Group**

The DeNDRoN Coordinating Centre will establish a working party that will be responsible for overseeing the development and monitoring of the progress of active PPI in the DeNDRoN. The PPI Road Map Group will comprise of experts who have experience and expertise in involving people affected by these conditions in research and service development; people affected by these conditions with some experience of being actively involved in research;

representatives of dementia, Parkinson's, MND and Huntington's medical health charities; and representatives of the DeNDRoN Coordinating Centre.

The remit of the PPI Road Map Group will be:

- To ensure that the identified research interests and priorities of patients, carers and the public are fully taken into account within the work of DeNDRoN.
- To operate at a strategic level and assist with the development of overall DeNDRoN policy in respect of improving clinical research for the benefit of people affected by these conditions.
- To review and amend as necessary the 'aims', 'principles' and 'objectives' of our PPI programme as set out in this document.
- To develop a 'road map' of how the DeNDRoN Coordinating Centre should undertake to develop the PPI programme in order to deliver the 'aims', 'principles' and 'objectives' as agreed by the Road Map Group.

The members of the PPI Road Map Group will be asked to consider and submit comments on the 'aims', 'principles' and 'objectives' prior to the first Road Map Group meeting. These comments will then be considered at the meeting with the intention of signing off revised 'aims', 'principles' and 'objectives'. The Group will then consider and debate the creation of a 'road map' by which the DeNDRoN Coordinating Centre will look to achieve these 'aims', 'principles' and 'objectives'. It is intended that a draft 'road map' will be ready for circulation following this first meeting.

The Road Map Group will meet quarterly for the first year, with the frequency of meetings to be reviewed at that point.

## **5. Co-ordination of our Patient and Public Involvement Programme**

The coordination of active PPI presents a particular challenge for DeNDRoN. There are a number of issues which need to be addressed to enable people affected by neurodegenerative diseases to become more actively involved in clinical research. Although many of these issues cut across all the diseases incorporated into DeNDRoN, there are also issues to consider that are specific to each disease. We are in the process of developing our strategy for coordinating PPI across the Network. This strategy will combine tackling cross cutting issues with providing disease-specific support where appropriate. We are currently developing this strategy in conjunction with our non-statutory disease association partners, and with the UKCRN and Department of Health. The PPI Road Map Group will further develop this part of the strategy and incorporate this into the road map.

The DeNDRoN Coordinating Centre will appoint an officer to act as the PPI Coordinator of this programme of work. The post holder will be responsible for using the road map to develop and deliver our PPI programme, across all diseases of the Network.

## **6. The Patient and Public Involvement Forum**

Depending on the agreement of the PPI Road Map Group, one of the initial objectives of the Patient and Public Involvement Programme is to establish and support a group of patients, carers and other people affected by these conditions. Core activities of this Programme will be channeled through, and delivered via this 'Forum'. The Patient and Public Involvement Forum (PPI Forum) will be supported by the PPI Coordinator. The Coordinating Centre will

advertise nationally for membership of the PPI Forum through national disease associations and informal networks.

The PPI Forum will have a number of key functions including:

- To act as a forum for discussion, generating ideas to ensure that the identified research interests and priorities of patients, carers and the public are fully taken into account within the work of the DeNDRoN.
- To provide a supportive environment in which people can become increasingly involved in all stages and all levels of the clinical research process in respect of improving clinical research for the benefit of patients, carers and the public.
- To produce, with the support of the Road Map Group, best practice guidelines about different methods and levels of active involvement of people affected by these conditions in clinical research.
- To provide input from people affected by these conditions into the DeNDRoN Clinical Study Groups (via CSG membership). [See Appendix 1]
- To provide input from people affected by these conditions into the adoption of clinical studies into DeNDRoN's portfolio (via Adoption Panel membership).
- To provide input from people affected by these conditions into the DeNDRoN Operational Steering Group (via OSG membership).
- To produce, with the support of the Road Map Group, a training programme for clinical researchers and healthcare professionals involved in DeNDRoN activities, to facilitate active patient and carer involvement in their research; and develop the skills of researchers.
- To provide input from people affected by these conditions into ad hoc projects.

The PPI Forum members will receive ongoing training and support to help them fulfill any specific roles they take on, and to become as effective as possible in using their views, perspectives and experience to improve clinical research for the benefit of patients, carers and the public. A mentoring programme will be developed to support involvement in scientific committees, with arranged pre- and post-meeting briefings.

A DeNDRoN-specific induction plan will be established for all those joining the PPI Forum, and members of the PPI Forum will also be encouraged to attend appropriate courses being run by UKCRN (e.g. An Introduction to Clinical Research; Critical Appraisal Skills; Developing Best Practice for Patient and Public Involvement in Research).

## **7. Communication**

- The DeNDRoN Coordinating Centre will establish a dedicated PPI area within the DeNDRoN website and a newsletter to inform patients, carers and the public about neurodegenerative disease research.
- Other methods of communication will be developed to inform study participants about the progress of the study that they are involved in as well as the outcomes, and in addition to other ongoing studies.
- The PPI Coordinator will lead on the development of these communications channels with the input of the RMG, and support of the UKCRN PPI Lead.

- The PPI Coordinator and DeNDRoN Coordinating Centre will work closely with the national press offices and local branch networks of the relevant patient and carer disease-specific charities to develop appropriate communications channels with these partner organisations.

Piers Kotting  
DeNDRoN Assistant Director  
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## **Appendix 1**

### **Role of Clinical Studies Group lay members**

#### **1. ROLE**

Clinical Studies Group lay members are expected to:

- Provide their perspective as a person affected by neurodegenerative diseases into the development, management and reporting of individual clinical studies.
- Offer advice on the development of active PPI.
- Assist with the prioritisation and development of the overall portfolio of clinical studies.
- Feedback to the PPI Forum, relevant issues arising from the Clinical Studies Groups.
- Respect any requests for confidentiality, and declare any conflicts of interest if they arise.

#### **2. DUTIES**

Clinical Studies Group Members are expected to contribute to the activities of the Clinical Studies Group, its sub-Groups or associated working parties by:

- Actively engaging with trials within the Group's portfolio, for instance through offering information and advice to other patients on request, and participating in discussions of findings as appropriate.
- Generating ideas for new clinical studies/identifying priorities and research gaps.
- Contributing to the development of high quality applications to funders through the review of trial ideas and protocols submitted to the Group.
- Contributing to consultation exercises (eg NICE) undertaken by the Group or DeNDRoN as requested.
- Contributing to the Group's annual report.
- Providing advice to the Chair as required.
- Reading Clinical Studies Group paperwork.
- Attending Clinical Studies Group meetings.

A Mentor will be available to provide support to lay members on Clinical Studies Groups. The role of the Scientific Mentor is:

- To be available for lay members to contact by telephone before and after each meeting.
- To welcome lay members to each meeting of the Group.
- To answer questions from lay members during the meeting.