

# Sheffield Motor Neurone Disease Research Advisory Group

Abstract: The presentation will be in the form of a poster and it aims to educate people about the group that is now supporting Motor Neurone Disorders (MND) researchers through Yorkshire and Humber to:

- Enable patient and carer perspectives to be included in research proposals
- Identify and prioritise research topics important to patients and their families
- Improve recruitment to research studies
- Aid researchers to write clear lay summaries and study information sheets
- Help share research findings with a wider audience
- Raise awareness of MND research.

The group has increased its activity substantially since its development in 2009 and would like to share its experiences and ideas with other individuals involved in patient and public involvement work to encourage the innovative methods they have used.

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**Public and patient  
involvement (PPI) as a**

# challenge and a tool in European Joint Programming Initiative on Neurodegenerative Disease Research (JPND)

Abstract: Neurodegenerative diseases such as Alzheimer's and Parkinson's are a truly global challenge. Most of these diseases remain incurable and are strongly linked with ageing populations. Dementias alone affect more than 7 million people in Europe and their care is estimated to cost €130 billion a year.

The EU Joint Programme – Neurodegenerative Disease Research (JPND) was established in 2009 as the pilot of the Member State-led Joint Programming Initiatives (JPI) to enable participating EU Member States to work together on the challenge of age-related neurodegenerative diseases, in particular Alzheimer's. In the past five years, JPND has become a global initiative with 28 countries now participating.

JPND countries work together very effectively in a number of priority areas with activities moving forward in parallel, creating the necessary trust and alignment between the 28 participating countries.

In 2012 it was decided by the Management Board of JPND that Public and Patient Involvement (PPI) should be integrated in JPND joint actions. Since then experiences have been gathered regarding the special challenges that arise from collaboration cross border in implementing PPI:

- Differences in culture and tradition across JPND member

countries must be considered. Cross cultural and social differences will have an impact on the way individuals with ND become visible and are accepted or stigmatized.

- Consideration should be given to the different starting points of JPND member countries in regard to implementation of PPI guidelines.
- The JPND initiative on PPI also considers the following issues – some of which are general to PPI in research – some of particular importance within research on Neurodegenerative diseases

Due to the insidious onset of neurodegenerative diseases and the enormous burden they inflict on patients, families and carers, there is a clear argument for active patient and public involvement in JPND research initiatives.

- Several issues, especially relevant to ND need to be taken into consideration for the implementation of PPI in specific ND including: cognitive impairment; rapid decline of health and function; lack of speech and other communication skills; dependency on carers and families; genetic risk factors.
- The appropriate levels of PPI in the various types of JPND research should be considered and investigated, that is PPI in basic, clinical and health and social services research.
- PPI should be treated as an ethical imperative in itself – that is to initiate the process, although evidence of its impact in ND research has been raised in some literature areas.
- It is important to seek better health outcomes as a consequence of PPI in ND research. At the same time, the difficulty of linking PPI in ND research to changes in health outcomes should be acknowledged. Therefore, the timeframe for measurement of the impact of PPI should be very long.
- Over time, the impact of PPI on research will influence

the role of the researchers.

- The interests of the Pharma- and Medico- and Welfare-technology industry in PPI should be considered. The example of the European Patients' Academy on Therapeutic Innovation Innovative Medicines Initiative (EUPATI-IMI) project should be monitored.
- Patients and carers may play a role in the process of feedback of study results to participants, to other stakeholders, and to the public in general.

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# The role of INVOLVE for developing the Framework for User Involvement in Research in Denmark

## **Abstract:**

Denmark is on the top five list among nations for clinical research. It is documented that the Danish population has a very positive attitude towards participation in clinical research. In 2010 it was recognised that this attitude was just one aspect of an active user involvement in research.

This presentation will describe how and why the inspiration from INVOLVE has played a crucial role for the plans for implementation of a comprehensive user involvement in research in Denmark.

# **Faith communities and ambulance services**

We are organising a major summit which will bring members of Leicester's diverse faith communities and Ambulance service managers and paramedics together for the first time. This will be the first time such an event has been held in the UK. It will take place in August 2008. The objectives are to generate community engagement in the work of the Ambulance Trust, identify key issues, raise awareness of the links between faith and health, and foster improved understanding and relationships between the Ambulance services and faith communities. The Leicester Council of Faiths and Charnwood Community Arts are working with the Ambulance service to hold this event.

The presentation will let people know how the summit was organised, and how people from faith communities were involved. People can also find out how ambulance services have improved as a result listening to people of faith.

People will learn why faith is important to many people when they are ill, and how ambulance services can respect the religious wishes of the public whilst still carrying out their duties.

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# **Ambulance ambassador for BME elders**

Many ethnic minority elders are unsure when to contact emergency health services and anxious about what will happen if they dial 999. This means that sometimes the ambulance is called too late.

Community groups have said that they want to know more about the early signs of life-threatening conditions such as heart attacks, stroke and hypothermia. They want to understand what happens when they dial 999, and they want to be reassured that the Ambulance staff will treat them with dignity and respect.

In this presentation people will learn about a special “Ambassador” post that has been established within the Ambulance Trust to work specifically with African, Caribbean and Asian elders. They will learn how the Trust has built its relationship and understanding of the health needs of these elders, and enhanced their effective use of 999 and patient transport services.

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