

## Patient Consultation Exercise by South West DeNDRoN

### INFORMATION SHEET

#### What is South West DeNDRoN

South West DeNDRoN is the regional branch of the national Dementias and Neurodegenerative Diseases Research Network. It is funded by the Department of Health and its role is to improve the delivery of research into dementias, Parkinson's disease, Motor Neurone disease, Huntington's disease and Progressive Supranuclear Palsy. It coordinates and provides trained staff to run studies.

#### The Purpose

The purpose of this consultation exercise is to conduct a 'listening exercise' during May 2012 – Sep 2012 with patients and families. Feedback will directly influence future research projects.

#### Geographical area covered

SW DeNDRoN covers Cornwall, Devon, Avon, Somerset, Wiltshire and Gloucestershire. In view of time and resource limitations, this consultation exercise is focussing on the following regions, although analysis and reporting will be framed so as to be relevant to stakeholders across the whole region:

- Dementias – Plymouth, Bristol and Exeter regions
- Parkinson's disease – Plymouth, North Devon region
- Motor Neurone disease – Plymouth, Bristol and Exeter regions
- Huntington's disease – Plymouth, Exeter region

#### How are we doing this ?

During May – Sep 2012 we are meeting with patients and families through existing forums and events, for example dementia cafés, local support groups, regional events etc. We may also conduct face to face and telephone semi structured interviews using a simple questionnaire.

We hope to collect examples of good practice as well as examples of challenging situations.

#### Tell me about the new Patient Advisory Panel

We are developing a new virtual Patient Advisory Panel to provide leadership on DeNDRoN's research activities across the South West. It works in partnership with many other local and regional patient advisory groups for dementias, Parkinson's disease, Huntington's disease, Motor Neurone disease and Progressive Supranuclear Palsy. Together we offer patients and the public the unique opportunity to be involved in a variety of ways, from regional to local level.



**What are we asking patients and families ?**

1. How would patients like to find out about opportunities for being involved in research ?
2. What would encourage patients to be involved in research ?
3. When would patients be comfortable to start discussing with a health professional opportunities for being involved in research ?
4. What information would be interesting in a research newsletter for patients and families ?

Additionally :

- Would they like to join SW DeNDRoN's Patient Advisory Panel ?
- Would they like to sign up for SW DeNDRoN's newsletter ?
- Would they like more information on taking part in a study themselves ?

**What would it mean to take part in this consultation exercise ?**

1. Always being given the choice about being involved, and being able to change your mind at any time.
2. Completing a questionnaire and having a short discussion with the project worker about improving public involvement in research study. This may mean taking part in a telephone or face to face discussion.

**What will happen to the information provided ?**

The information provided will be stored securely in accordance with NHS information governance regulations. The results of the exercise will be written up in September and available to the stakeholders and to everyone who participated in it.

**Who is the main contact ?**

Alison Fowler - Project Manager South West DeNDRoN

Tel: 0117 3784239 Mobile:07919 213154 E-mail: [south-west@dendron.org.uk](mailto:south-west@dendron.org.uk)

Website: [www.dendron.org.uk/rn/sw.html](http://www.dendron.org.uk/rn/sw.html)



## Patient Consultation Exercise by South West DeNDRoN

**Please complete and return this form to:** SW DeNDRoN, AWP Research and Development Office, The Blackberry Centre, Blackberry Hill Hospital, Manor Road, Fishponds, Bristol BS16 2EW

**Or e-mail:** [south-west@dendron.org.uk](mailto:south-west@dendron.org.uk)

**Or complete our online survey:** [www.dendron.nihr.ac.uk/south-west](http://www.dendron.nihr.ac.uk/south-west)

**1. How would you like to find out about opportunities for being involved in research ?** Please tick box(es)

- GP..... Practice Nurse ...  Hospital consultant .... Hospital Nurse ...
- Pharmacy... Public library ..... Support groups ..... Dentist .....
- Radio, TV... Newsletters ..... Newspapers..... Parish activities...
- Friends and neighbours ..... Other .....

**2. What would encourage you to be involved in research ?** Please tick box(es)

- Personal reasons - *“doing something positive in a negative situation”* .....
- Access to research teams and consultants.....
- Opportunity to increase knowledge about the disease .....
- Opportunity to test new ways of managing the disease .....
- Other .....

**3. When would you be comfortable to start discussing with a health professional opportunities for being involved in research ?**

**4. What information would be interesting in a research newsletter for patients and families ?**



## Expression of Interest to be involved in South West DeNDRoN

**Please complete and return this form to:** SW DeNDRoN, AWP Research and Development Office, The Blackberry Centre, Blackberry Hill Hospital, Manor Road, Fishponds, Bristol BS16 2EW

**Or e-mail:** [south-west@dendron.org.uk](mailto:south-west@dendron.org.uk)

### Information about our DeNDRoN Patient Advisory Panel

We are developing a new Patient Advisory Panel to provide leadership on DeNDRoN's research activities across the South West.

It works in partnership with many existing local and regional patient advisory groups for dementias, Parkinson's disease, Huntington's disease, and Motor Neurone disease.

Together we offer patients and the public the unique opportunity to be involved in a variety of activities at local and regional levels. More information on our Patient Advisory Panel is on our website [www.dendron.org.uk/rn/sw.html](http://www.dendron.org.uk/rn/sw.html)

Please tick box(es)

**I am interested in joining your DeNDRoN Patient Advisory Panel** .....

**I would like to receive your newsletter** .....

(newsletters are sent by e-mail unless you indicate that you would like to receive them by post)

**I would like to know how to be involved in a research study** .....

**Name** .....

**E-mail** .....

**Address** .....

**Phone number** .....

### **Data Protection**

Any personal information submitted by you will be held by DeNDRoN within NHS systems for the purpose of research and development. It shall be processed in accordance with the principles of the Data Protection Act 1998 and may be stored for up to 20 years. If you have expressed an interest in becoming involved in a research study, DeNDRoN will contact you for further details. We would only share your information with other NHS and non-NHS organisations for your benefit in a secure and appropriate manner. You have the right to withdraw your information from DeNDRoN at any time. To discuss what DeNDRoN does with your data, please contact Mary Griffin on 0117 3784239.

