

Patient Advisory Panel Strategy & Terms of Reference

Purpose of this paper

This paper sets out the strategy for the SW DeNDRoN Patient Advisory Panel only. The strategy for PPI involvement in SW DeNDRoN is a separate document. Please refer to the Terms of Reference for the Patient Advisory Panel, V1 15/11/12.

Vision

The South West Dementia and Neurodegenerative Disease Network (DeNDRoN) is a local clinical research network. We support recruitment to clinical studies in dementias and neurodegenerative diseases, including Parkinson's disease, Huntington's disease, and motor neurone disease. Our vision is for every patient with dementia or neurodegenerative disease to have the opportunity to participate in high quality clinical research. This can mean taking part in a clinical study, or getting involved in a variety of ways. The Patient Advisory Panel is 1 way to get involved and membership is open to patients, carers, family members and members of the public. Together we offer patients, families and the public the unique opportunity to be involved in a variety of ways, from regional to local level.

Role of the Patient Advisory Panel

The Patient Advisory Panel provides leadership on DeNDRoN's research activities across the South West. The Patient Advisory Panel will:

1. Consult about studies, patient information sheets
2. Make suggestions on how to increase patient enrolment to studies
3. Explore ideas about what should be researched
4. Help DeNDRoN build and expand its links with local and regional patient groups
5. Explore topics and themes relating to research
6. Contribute to the production of newsletters and e-bulletins
7. Give patient/carer representation on various clinical and non-clinical groups across South West DeNDRoN
8. Be a voice representing the south west in national forums
9. Contribute to study design and preparation of bids
10. Reflect on personal experience in relation to study design or development

Strategy

This strategy has been developed from comments and feedback recorded at our launch meeting on 5 October 2012. From October 2012 our aim is to develop the Patient Advisory Panel and establish it as a focussed, useful and integral part of SW DeNDRoN. We also want to work in partnership with many other local and regional patient involvement groups to ensure that as many people as are interested have the opportunity to contribute. The following table sets out how we will achieve this and the success measures.

Aim	Action	Timescale	Responsibility	Metrics
1. Consult about studies, patient information sheets	<ol style="list-style-type: none"> Results of studies DeNDRoN involved in circulated to Patient Advisory Panel. All requests for lay reviewers to go through Patient Advisory panel. Publicise role of panel as people with first hand experience, and who can explain what being involved in research is about. 	As required	SW DeNDRoN & Patient Advisory Panel	<ol style="list-style-type: none"> Network Manager/ PPI Coordinator will keep a record of how many requests are sent to the Panel and feedback from the researcher. Network Manager/ PPI Coordinator & Patient Advisory panel to decide what publicity is required.
1. Make suggestions on how to increase patient enrolment to studies	<ol style="list-style-type: none"> Workshop studies that are failing to recruit. Hold focus groups to discuss study design. 	As required	Patient Advisory Panel	<ol style="list-style-type: none"> Network Manager/ PPI Coordinator will keep a record of approaches by researchers.
3. Explore ideas about what should be researched	<ol style="list-style-type: none"> Publicise the role of the panel to researchers. Group research tests with social experience – cost Needs ethical approval, could be built into proposal 	As required	SW DeNDRoN Patient Advisory Panel	<ol style="list-style-type: none"> Network Manager/PPI Coordinator will record how proposals by panel are taken forward.
4. Help DeNDRoN build and expand its links with local, regional patient groups in the SW and other regional/national groups outside the SW	<ol style="list-style-type: none"> Access to training and training development. Publicity for the panel Circulate press releases. Let researchers in the SW know. Circulate website links. 	As required	SW DeNDRoN & Patient Advisory Panel	<ol style="list-style-type: none"> Network Manager/ PPI Coordinator to find out what training is available. Patient Advisory Panel members to identify training needs.

Aim	Action	Timescale	Responsibility	Metrics
5. Explore topics and themes relating to research	1.	As required	Patient Advisory Panel	
6. Contribute to the production of newsletters and e-bulletins	<ol style="list-style-type: none"> 1. Requests for articles to be sent to the Patient Advisory Panel. 2. Patient Advisory Panel members to feedback on SW DeNDRoN publications. 3. Use Patient Advisory Panel as speakers for the condition they represent. 	As required	SW DeNDRoN & Patient Advisory Panel	<ol style="list-style-type: none"> 1. Network Manager/ PPI Coordinator will record how proposals by panel are taken forward.
7. Give patient/carer representation on various clinical and non-clinical groups across South West DeNDRoN	<ol style="list-style-type: none"> 1. Advertise vacancy for PPI member for SW DeNDRoN Project Board, previously Steering Committee. 	As required	Patient Advisory Panel	<ol style="list-style-type: none"> 1. Network Manager/ PPI Coordinator to advertise vacancy on website and in newsletter. 2. Keep list of NIHR patient Ambassadors. 3. Formally inform DeNDRoN CC of our Patient Advisory Panel.
8. Contribute to study design and preparation of bids	<ol style="list-style-type: none"> 1. Requests from researchers will be sent to the Patient Advisory Panel. 2. Focus groups will be arranged by SW DeNDRoN as required. 	As required	Patient Advisory Panel	<ol style="list-style-type: none"> 1. Network Manager/ PPI Coordinator will keep a record of approaches by researchers.
9. Reflect on personal experience in relation to study design or development	<ol style="list-style-type: none"> 1. Create case studies that illustrate the personal experience. 	As required	Patient Advisory Panel	<ol style="list-style-type: none"> 1. Network Manager/ PPI Coordinator to advertise vacancy on website and in newsletter.

Measuring the success of the Patient Advisory Panel

The success of the Patient Advisory Panel will be judged on the achievements noted above. If after 12 months the success measures have not been met, SW DeNDRoN in consultation with the Patient Advisory Panel will implement the following actions:

1. Review membership of the Patient Advisory Panel.
2. Review the Patient Advisory Panel Strategy.
3. Consider other models of PPI involvement.
4. Consider a revised format of the Patient Advisory Panel.

Patient Advisory Panel Terms of Reference

Purpose of the paper

This paper sets out the proposed aims, membership, responsibility, activities and modus operandi of the SW DeNDRoN Patient Advisory Panel from November 2012.

1. The SW DeNDRoN Patient Advisory Panel

South West DeNDRoN's Patient Advisory Panel works in partnership with many other local and regional patient involvement groups. It offers members a variety of ways for giving their views and advice on how to make research relevant to patients and carers.

1.1 Membership

For the sake of confidentiality, names will not be listed in this document.

- Members of the public, carers and patients who have expressed a wish to join the panel and completed the relevant consent forms.
- South West Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) Network Manger
- South West Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) PPI representative (when appointed)

There is no set membership for the panel and no minimum number. However, for the organisation of face to face meetings, a minimum of 10 members are required to attend. Members can withdraw their membership of the panel at any time. Membership will be reviewed every 12 months to ensure that there are enough members to represent all 4 disease areas. Being unable to attend face-to-face meeting does not mean members cannot contribute to the panel. Contribution via post or email is just as important for the success of the panel.

1.2 Role

The SW DeNDRoN Patient Advisory Panel will:

- Consult about studies, patient information sheets
- Make suggestions on how to increase patient enrolment to studies
- Explore ideas about what should be researched
- Help DeNDRoN build and expand its links with local and regional patient groups
- Explore topics and themes relating to research
- Contribute to the production of newsletters and e-bulletins
- Give patient/carer representation on various clinical and non-clinical groups across South West DeNDRoN
- Contribute to study design and preparation of bids
- Reflect on personal experience in relation to study design or development

1.3 Objectives

To offer patients, families and the public the unique opportunity to be involved in a variety of ways, from regional to local level. Specifically:

- To provide leadership on DeNDRoN's research activities across the South West.
- To work in partnership with many other local and regional patient involvement groups for dementias, Parkinson's disease, Huntington's disease, and motor neurone disease.

1.4 Frequency and operation of meetings

- Face-to-face meetings will be held every 12 months in either Exeter or Taunton, a midway point between Gloucester and Cornwall.
- Refreshments will be provided by SW DeNDRoN.
- Meetings by teleconference will be held on an ad hoc basis.
- Focus groups will be arranged as required by researchers.
- Minutes will be kept and agreed by Panel members.
- Copies of the minutes may be circulated to additional relevant parties by agreement of the Panel.

1.5 Method of communication

- Communication between SW DeNDRoN and the Patient Advisory Panel will be by email, unless a member has specified to receive information by post.
- Emails will be blind carbon copied so that email addresses are not revealed, unless panel members state otherwise.
- SW DeNDRoN will pick up the cost of the teleconference calls. The details for teleconferencing are:
 - Telephone number:
 - PIN code:
- Details of panel members will not be passed onto researchers by SW DeNDRoN.
- A facility on the SW DeNDRoN will be created for members to log in and access information.

1.6 Requests from researchers

- Requests from researchers will come with a lay summary provided.
- A glossary of terms will be provided to explain acronyms.

1.7 Expenses

Expenses will be paid as follows:

- Travel expenses will be paid for costs incurred getting to and from face-to-face meetings.
- SW DeNDRoN will pick up the cost of teleconference calls.
- Business reply envelopes are provided for any correspondence by post.
- Other expenses will be paid in line with the "Guidance notes for reimbursing lay members in LRNs Version 1.1, December 2007."

1.8 Other

Agreeing to become a Patient Advisory Panel member does not mean agreeing to join a clinical study or being pressurised to join a clinical study.