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# Guidance on recruitment of patient/public members on DeNDRoN Local Research Network steering committees

## Introduction

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This is a series of suggestions about incorporating patient/public members into DeNDRoN committees; many DeNDRoN committees have a specific requirement to include these. The aim is to appoint (a minimum of) two patients, carers or other people as members of key DeNDRoN committees, using selection aimed at achieving a balance of patient/public perspectives.

**This is a joint learning process.** Some guidance included here has been drawn from other clinical research topics, but may need to be adapted to suit the circumstances of dementia and neurodegenerative disease research. Staff and patients in every local and national component of DeNDRoN will only really learn in practice what works well – and what doesn't – to build up patient and public involvement within its committees.

DeNDRoN's national PPI Working Group supports the principle of selection of members. It has also recommended which committees should be seen as high priority for including patient/public membership. These include LRN Steering Committees.

## The benefits of involving patient/public members in DeNDRoN local and national committees

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DeNDRoN is working to engage with patients and the public in a number of different ways through which they can meaningfully contribute to its work.

### **Involving patients and the public as members of its committees can achieve the following:**

- Include additional patient and carer perspectives, which might otherwise be overlooked
- Additional knowledge for the committee from the individual's experience and contribution
- Identify and prioritise research topics that are important to patients
- Help with training staff
- Improve recruitment to research studies
- Help in identifying improved measures for research outcomes
- Give the committee a more authoritative voice
- Build public credibility and trust in clinical research, and improve external evaluations of DeNDRoN
- Insight into further possibilities for involving patients and carers to have a say in DeNDRoN

# Patient and public members of the Local Research Network Steering Group

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## **The Local Research Network Steering Group:**

- Advises on the development of strategies, activities and approaches to research across the Local Research Network area
- Oversees the strategic planning and implementation of research studies adopted
- Monitors research governance - ensuring good quality research
- Advise on the financial planning of the Local Research Network

Whilst describing here the roles that those who become patient/public members of the Steering Group may be expected to undertake, it needs to be stressed that many of these apply not just to the patient/public members, but equally to all committee members as a partnership.

Patient and public involvement in DeNDRoN is gradually developing, and getting it right will be a learning process for us all. What we don't get right now, we will hope to change in the future.

## **The core role of patient/public representatives**

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The core role of a patient/public member is to contribute to the development of DeNDRoN locally from the point of view of someone with direct or indirect experience of dementias and/or neurodegenerative diseases.

### **Patient/public members on the Steering Committee will be able to contribute to the development of the LRN Steering Group's work as follows:**

- Attend relevant Steering Group meetings
- Work constructively as part of the Steering Committee to foster the aims for the LRN
- Read through the papers and other items beforehand
- Read and consider consultation documents, to provide comments on the consultation documents where appropriate from a patient/public perspective
- Discuss and comment on items during meetings, and raise issues for consideration
- Take into account the responsibilities, viewpoints and expertise of other members
- Provide a patient/public perspective on Steering Committee deliberations
- Consider methods for wider patient and public involvement in the strategic development of the Local Research Network
- Contribute to training of new staff
- Attend occasional sub-group meetings if appropriate, or external events/conferences and report back to the group
- Advise on LRN newsletters and general publicity for the Local Research Network and on dissemination of research results
- Respect any requests for confidentiality, and declare any conflicts of interest if they arise.
- Contribute to reviews and evaluations of the Steering Committee's work

## The person

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People interested in becoming patient/public members will come from different backgrounds. Below is a wide-ranging list of skills and qualities for the role. It is recognised that individuals will have different combinations of skills to contribute. Selection will aim at balancing different characteristics, although obviously not all will be included.

### **Essential skills and qualities of patient/public members**

The most important personal skill for the role is a willingness to bring to the committee a balanced understanding of the wide range of different perspectives which dementia and neurodegenerative disease patients, carers and the wider public will have.

### **Patient/public members should have direct or indirect experience of dementias and/or neurodegenerative diseases in one of the following ways:**

- as a patient, carer, ex-carer, family member, or friend of those who have been a patient and/or who have participated in research,
- as a member of the public who may be involved in clinical and health research programmes related to dementias and neurodegenerative diseases, or affected in other ways by health or clinical research issues in dementias and neurodegenerative diseases,
- as a member of the wider public with relevant experience of patient and public involvement

### **Other essential qualities**

- Able to give a balanced viewpoint, including an understanding of a range of different perspectives on dementia and neurodegenerative disease
- Able to travel to attend meetings, and to carry out other activities, such as reviewing documents.

### **Desirable personal qualities of patient/public members**

- Medical charity experience is helpful, although patient/public members - like other members - are chosen because of their individual experience, not because of their affiliations or relationships with other organisations
- Experience of patient and public involvement
- Keen interest in healthcare in the UK
- An understanding of clinical research processes
- Good communication and team-work skills, and a potential willingness to speak in public
- Experience of committee work
- Experience of running things, and management experience
- Patient/public members will find it highly advantageous to have access to email, the internet, and a printer, and be reasonably proficient in their use.
- Self confidence in a mixed group of professionals

## Other aspects of the role

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### Duration

It would normally be hoped that patient/public members would commit to up to three years, or at least one year. However, to ensure a full range of patient's health considerations can be taken into account, planned duration of membership may be shorter or open-ended.

### Remuneration

Membership of a Steering Group is unpaid. Reasonable travel expenses, that are agreed, will be reimbursed in accordance with DeNDRoN Expenses Policy or local policies where indicated. There is a separate guidance document on reimbursement of LRN patient/public member expenses.

### Raising concerns

If there is something about the Group or meetings that makes the person feel uncomfortable, to approach the Chairperson or Research Network Manager, or someone else appropriate

### Conflicts of interest

Members shall be required to disclose any involvement with individuals, government bodies, commercial interests or third parties which could lead to a conflict of interest with the work of the Steering Committee. A conflict of interest doesn't stop someone from being a patient/public member.

### Confidentiality

Some papers circulated for DeNDRoN meetings are considered to be confidential, even if not marked as such. Many patient/public members will be in contact with other patients and people affected by a particular condition, and will feel there are general issues, arising from the meeting, that they would like to discuss. Indeed this will be an important avenue to provide a broader patient/public perspective on many issues.

Things that may be discussed with others outside the meeting could, unless indicated otherwise by the Chairperson, include identifying priorities for research activities, progress in a particular area of research, and publicly available details about proposed trials.

Members should not communicate any potentially confidential information that they learn as a result of being a member of the group. In particular, proposed trial-specific information should only become public once the protocol is published. Members should always seek clarification first from the Chairperson or Research Network Manager if unclear.