

# **Guidance on Recruitment of Patient/Public Members on DeNDRoN Local Research Network Steering Committees**

## **A Joint Learning Process**

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

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## **Introduction**

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**

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

# Issues for LRNs

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## **Existing members**

This guidance applies to new appointments. Where LRNs have already included one or more patient/public representatives in steering committees, these people should be welcome to continue in their existing posts.

## **Individual LRN approaches**

Some LRNs are looking at informal arrangements, such as rotating membership, or patient/public members meeting with the Chairperson and LRN Manager separately from the steering committee itself. Such creative approaches are welcomed, provided that they are built upon the formal starting point of (a minimum of) two patient/public members being full members of the LRN Steering Committee at any given time.

## **Observers**

Where considered appropriate, potential patient/public members may be invited to join the LRN Steering Group as an observer member for a while before formal membership is considered.

## **Patient and Public Panels**

From the expressions of interest received, LRNs could build a reference panel of individuals who are not committee members, but are prepared to be to be involved in various informal ways, either by mail or face-to-face. People who are not successful in getting on to the Steering Group might be interested in joining such a panel.

## **Medical charity representation**

Chairpersons should properly view all patient/public members as representing their individual viewpoints. Patient/public members, like most other committee members, are chosen because of their individual experience, not because of their affiliations or relationships with other organisations. Nevertheless, in practice, patient/public members may have been recommended by or closely identified with a specific medical charity, and naturally they will often aim to reflect that organisation's views.

## **A note on terminology**

The phrase 'patient/public member' is used here as a shorthand attempt to encompass patients, carers, ex-carers, relatives, potential patients and the wider public. The term 'lay member' is nowadays often avoided, and patients rightly emphasise that they are in fact the principal experts.

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

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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

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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 (approximately {{X}} per year)
- 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.

# Calling for patient/public members

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## Where to advertise

Typically, publicity via medical charities will be especially important, but choosing other methods to use will depend on the particular balance your committee wants to achieve.

### Here's a range of possible avenues for calling for new members:

- Local/regional medical charities and patient representative organisations. Note that medical charities might occasionally want payment to cover postage costs
- Informal LRN contacts with interested individuals and community groups
- Local and national DeNDRoN websites
- Involve ([www.invo.org.uk](http://www.invo.org.uk)) is funded by the Department of Health, and aims to promote and support active public involvement in NHS, public health and social care research
- Press releases
- Research-related organisations, such as Research Development Support Units and Clinical Trials Units
- NHS Trust Leads for Patient & Public Involvement and Leads for R&D
- PPI Local Involvement Networks and relevant community groups, including relevant ethnic community groups
- Distribution of flyers at research sites
- UKCRN
- Other Topic-specific RNs as appropriate

Under-represented geographical areas, clinical conditions, minority ethnic backgrounds or community groups might need special consideration.

Patient/public members, like all other members, are involved because of their individual experience and knowledge, not because of their affiliations or relationships with other organisations. Elsewhere, this document attempts to clarify the interpretation of confidentiality, whilst recognising that patient/public members will want to discuss some DeNDRoN issues externally to provide a broader patient/public perspective.

## The wording

The content, style and degree of formality of advertisements, press releases or calls for patient/public members on LRN Steering Committees will depend on the targeted audiences.

'Friendlier' wording may be preferred for leaflets or adverts, such as "Patients And Carers - Have Your Say In Research!", or "Patients and experts join forces to boost dementia and neurodegenerative disease research".

Here is one suggested format for wording.

### **Patient/public members sought for research steering committee**

DeNDRoN **{{AREA}}** Local Research Network wishes to recruit patient/public members to its managerial committee. We are committed to involving patients, carers and the public in our research activities, and therefore are seeking several people who wish to participate in our **{{NAME OF COMMITTEE}}**, which meets several times per year in **{{GENERAL LOCATIONS}}**.

#### **Each patient/public member must be one of the following:**

- a patient affected by dementias such as Alzheimer's disease, or neurodegenerative diseases such as Parkinson's disease, motor neurone disease, Huntington's disease, or others
- a carer or ex-carer
- other members of the public with some relevant experience

DeNDRoN is part of the UK Clinical Research Network. It facilitates the conduct of research trials in dementias and neurodegenerative diseases. DeNDRoN is a UK-wide initiative to promote collaboration between people affected by these diseases, academics, clinicians, NHS Trusts, researchers and funders. **{{MAYBE INCLUDE FURTHER BACKGROUND about the Local Research Network}}**

#### **The role**

The role of a patient/public member is to contribute to the development of DeNDRoN locally from the point of view of someone with experience of dementias and/or neurodegenerative diseases. This is an unpaid voluntary post, but agreed reasonable expenses will be reimbursed. Training opportunities will be available throughout the period of participation, and technical advice will be available while preparing for and participating in meetings.

The most important personal skill for the role is 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. An understanding of research processes, experience of committee work, and access to email are also highly desirable qualities for this role.

#### **Further details**

Informal enquiries may be made by telephoning: **{{.....}}**

Further information about the role and a very short application form is available by visiting our website at: **{{.....}}**.

If you wish to receive a paper copy, please telephone or email: **{{.....}}** or write to:

**{{.....}}**

Closing date: **{{.....}}** Interviews will be held on or around **{{.....}}**

## **Some other possible wording to consider for inclusion:**

### **Local patient and public panel**

We are also building a 'bank' of local individuals who would be prepared to be contacted occasionally to comment by mail on a draft leaflet or document, or when a local meeting is being planned. If you are not successful in getting on to the local Steering Group, you may be interested in joining this patient and public panel.

### **Patient and public involvement in local and national DeNDRoN**

Including patient and public membership in DeNDRoN committees is being developed at both local and national levels in the strategic management of research activities. At the local level this means involvement in operational steering groups, study management and information dissemination. At a national level, this means being part of decision-making about priorities, quality and relevance, study adoption, clinical studies groups, general DeNDRoN operational management, and advising on patient and public involvement.

### **Other details**

The call for members could include fuller details of number of meetings, venues, and other expected commitments

## **Description of DeNDRoN Local Research Networks for including in information to applicants**

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DeNDRoN has established seven Local Research Networks (LRNs) in England. In addition, 'Supplementary Resources' have been invested in several additional centres to provide further support for studies of motor neurone disease and Huntington's disease. There are other arrangements outside of England.

### **The Local Research Networks:**

- co-ordinate the recruitment of eligible patients for research studies
- employ and second research nurses and clinical trials officers to support the efficient set-up and delivery of studies
- seek to involve interested clinicians who may not have previously participated in clinical research
- provide support and training, to a recognised standard, for all teams conducting clinical research
- help with identifying and recruiting investigator sites for participation in studies
- offer support with obtaining local ethical approval, research and development (R&D) approval and arrangement of costings and contracts
- co-ordinate multi-centre sites within the network and monitor recruitment
- build on existing research infrastructure
- publicise ongoing trials
- performance-manage studies at local sites

### **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

## Application information which can be sent to interested people

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Versions of the role description and information contained in this guidance can be adapted to suit the LRN's needs, and sent out to interested individuals with a short application form.

If there is envisaged to be considerable interest, a short application form could be an essential part of the selection process. However, an application form is not essential, and indeed may be off-putting. The more "friendly" and concise the information sent out, the better. For example, if only one or two people have been identified, then a very informal-style interview may be most appropriate.

Name
Address
All useful phone numbers and best times to telephone
Email (not essential)
A brief overview of educational qualifications and work experience
Applicants do NOT need to attach a CV or similar.

**On the next page is a selection of potential questions for application forms. To help to emphasise that long answers are not required, only small text boxes could be included for answering each question.**

Mention that handwritten answers or typed are both acceptable.

### Reference:

**Please supply details of at least one reference**

Name and contact details of referee
Address
Telephone
Their email address, if any

## Selection from applications

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### **Here's a suggested selection of potential questions for application forms or which could equally be used in interviews.**

- Why are you interested in being a patient/public member of the LRN Steering Committee?
- What knowledge or experience related to dementias or neurodegenerative diseases have you had?
- What relevant experience would you bring to the committee? What contribution do you think you could make?
- Other experience or qualifications?
- Have you served on a committee before? What was your function?
- The role will involve reading and commenting on potentially complex documents. Can you give an example of when you have done that in the past?
- Any knowledge or experience of research?
- Do you have any knowledge of emails and computer skills?
- Any relevant health considerations such as around venues, transport, personal assistance, need for documents in accessible forms?
- Are you able to travel to meetings around the local area (agreed expenses can be reimbursed)?
- Are you prepared to travel outside the local area (e.g. to training days or conferences) occasionally?

## Interviewing

An interview of some sort will be an important part of the selection process.

This might last 10 or 20 minutes, depending on specific requirements. It must be stressed that the length and degree of formality of such discussions/interviews will depend on local circumstances, such as how many people are expressing interest. It could range from anything from a short one-to-one discussion with one or two people, to a very formal interview panel.

The elements of the role description can form the basic focus of interview questions. It outlines the purpose of the involvement and finds out more about the person's experience and background. The aim is to recruit people who are able to give a balanced viewpoint, who are able to carry out the activities for which they have been recruited and to ensure that the patient/public representation is made up of a variety of individuals from different walks of life.

## Following interview

Applicants will have displayed differing strengths and correspond to differing disease areas, in their answers.

The main selection criteria should be the essential skills and experience outlined in this document, and the desirable skills and experience.

Each application will be a balance of the wide range of desirable skills and qualities for the role. These can be judged and marked as either fully met, partly met, or not met. Selection should aim at incorporating as rich a mixture of these characteristics as possible in the committee. In cases where LRNs are considering rotating membership, there may be more scope for flexibility.

Successful applicants should be asked if they are willing to accept the place on the committee. One or more references may be checked. An agreement which confirms their place on the group could be sent with details of next steps and forthcoming meetings.

As mentioned earlier, from the expressions of interest received, LRNs could build a reference panel of individuals who are not committee members, but are prepared to be to be involved in various informal ways, in a patient/public panel. People who are not successful in getting on to the Steering Group might be interested in joining such a panel.

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## Support

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Training opportunities at UKCRN and elsewhere will be available throughout the period of participation, and technical advice in the form of scientific mentoring should be available while preparing for and participating in meetings. Research Network Managers and LRN On the DeNDRoN Coordinating Centre web pages, staff and patient/public members should be able to access separate guidance and suggestions around support.

### **New patient/public members should be provided with:**

- An overview of the LRN, and a local “Who’s who”
- An opportunity to meet other members of the group, and other Network staff and contacts
- A copy of the DeNDRoN Progress Report and recent DeNDRoN news items
- Guidance on expenses and reimbursement procedures
- Information about scientific mentoring available and other support
- Information about UKCRN and other training
- Assessment of initial support and training requirements, such as research knowledge, terminology, computer skills, confidence and presentation skills