

Parkinson's Research Interest Network at the University of Hertfordshire

Report on planning workshops, April and May 2024

The Workshops and Attendees

The aim of the Parkinson's Research Interest Network is to bring together people interested in research into Parkinson's, including people with Parkinson's, family and caregivers, professionals supporting people with Parkinson's, and researchers, to find out about and discuss Parkinson's research.

The purpose of the workshops was to seek the views of people with Parkinson's and other interested stakeholders in the local community on what types of events the network might arrange, and what practical issues should be considered when organising activities and events.

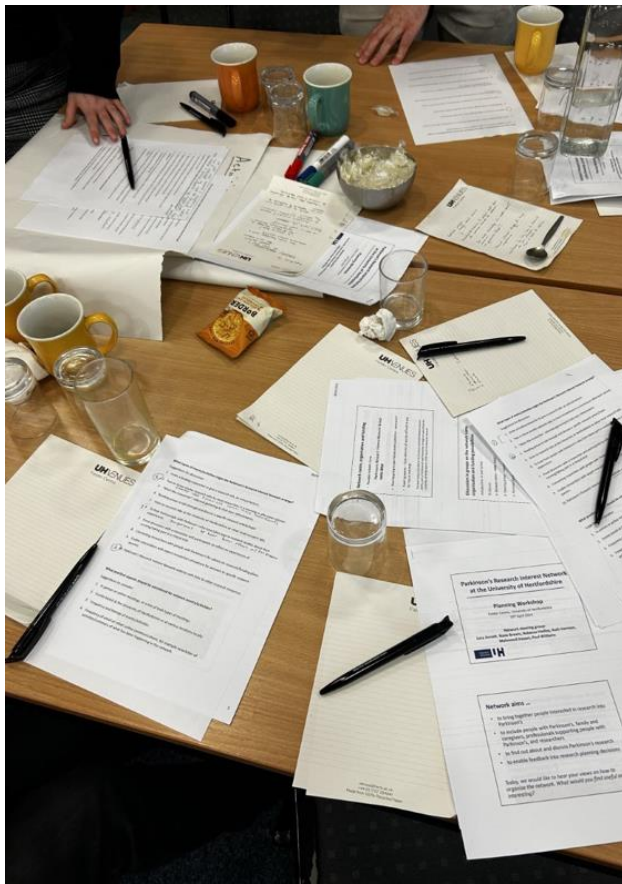
Workshops were held in-person at the Fielder Centre, Hatfield, on Wednesday 10th April, at Hampson Park Community Centre, Stevenage, on Saturday 4th May, and an online workshop on the evening of Wednesday 8th May 2024.

Attendees at the workshops included 26 people with Parkinson's, 13 family members, and 17 university academics or other professionals working with people with Parkinson's. Thirty people attended the Fielder Centre workshop, 31 Hampson Park Community Centre, and 10 online. (Note: some steering group members and other helpers attended more than one meeting).

The workshops were facilitated by Lucy Annett, supported by members of the steering group, Rosie Brewis, Becki Hadley, Ruth Herman, Mahmoud Iravani and Paul Williams. After introducing the Network aims and what is meant by evidence-based 'research', examples of research at the University of Hertfordshire relevant to Parkinson's were described, and reasons to be interested in research discussed.



Hampson Park Community Centre, 4th May 2024. Introducing the questions for discussion.



Fielder Centre, 10th April 2024. Table with discussion papers.

Participants at the in person workshops were asked to discuss in groups what types or events/activities the Parkinson's Research Interest Network might arrange, and what practical aspects should be considered in arranging these events. Participants at the online workshop were given a list of potential events/activities to consider and asked to vote on their preferences, and on what practical issues they thought important. Also discussed at the workshops were the network name, organisation and potential funding sources.

This report has been compiled from suggestions made by workshop participants recorded on the flipcharts and questionnaires at the in-person meetings, and from the transcript of the discussions and polls from the online meeting.

What types of events/activities would you like to see the Parkinson's Research Interest Network arrange?

You suggested:

- Focus on University of Hertfordshire/local research, not reinventing the wheel (e.g. not replicating Parkinson's research lectures already available online).
- Shorter talks by 3 or 4 researchers preferred, with explanations in plain words and plenty of time for questions and discussion. Some talks could be as short as 3 minutes to convey key points about a piece of research.
- Talks by people with Parkinson's, for example hearing from people who have taken part in research studies.
- Reading groups focusing on scientific reports of specific research studies.
- Input from network members on selection of topics and speakers, for example on recent news items.
- Topics for meetings – practical help for now, for example devices, what does taking part in research involve, how research is carried out, ethics issues in research, non-motor symptoms of Parkinson's, managing tremor, pharmaceuticals, exercise.
- Visits to local research labs, and to the Parkinson's UK Brain Bank (Imperial College, Hammersmith, London).

Our comments, looking forward:

We will aim to arrange a variety of types of events, including shorter research talks with time for questions and informal discussions.

In addition to talks by researchers, we will invite people with Parkinson's to talk about their experiences of taking part in research studies.

Events will focus on exploring and 'decoding' the research on a topic. While as university academics we are not qualified to give clinical advice or recommend the use of specific devices or treatments, we can help those interested in a topic understand what research has been done, and any limitations of that research, so you are better informed when making decisions about treatments in consultation with your clinician.

We will organise visits to research labs at the University of Hertfordshire and contact the Brain Bank to enquire about arranging a group visit.

What practical issues are important to you for Parkinson's Research Interest Network events/activities?

You suggested:

- In person meetings preferred, rather than online.
- About one in three meetings to be online for those unable to attend in person.
- Events about every 3 months/ 4 per year.
- Easy access to meetings very important, with good car parking and public transport.
- Buddies/volunteers to help with transport to meetings preferred rather than taxis.
- Varied locations for meetings, e.g. at venues already used by local Parkinson's groups.
- Communications by email preferred. WhatsApp group also suggested.
- Website with information about the network and links to research resources.

Our comments, looking forward:

The preference for in person rather than online events was very clear, although we recognise this was the opinion of those of you who attended the workshops in person. We will focus on in person network events, with some also online depending on the type of event and where the technology allows.

We will aim to arrange 3 or 4 network events each year.

We will try to use venues with easy access car parking and public transport, although venue bookings will depend in part on available funds. There is interest in attending events on the university campus. We will also aim to host some smaller events at different locations around the region, for example reading groups at venues used by local Parkinson's groups, so there is not as far to travel.

Interestingly, even though funds were available, no one took up the offer of booking a taxi and claiming back the fare to attend the workshops. Discussions at the workshops revealed some reluctance to use taxis with a preference for travelling with a 'buddy'. The process of claiming back the taxi fare may also be a barrier. We will explore whether community transport organisations/charities might assist with travel to events, again depending on available funds.

We will continue with email for network communications. A WhatsApp group might be possible in the future but is beyond the scope of what can be offered now given limited time and resources.

We will investigate options for setting up a website, in the first instance to provide contact details and information about future network events.

Network name, organisation and funding?

You suggested:

- Parkinson's Research Interest Network Group - **PARK-RING** was not liked by several discussion groups as the acronym suggests car parking. Also, the name was once associated with a boiler company!
- Include Herts or University of Hertfordshire in the name to emphasise a local network.
- Herts Parkinson's Research Network – **HPRN**, or Herts Parkinson's Research Interest Network – **HPRIN** to include the Hertfordshire connection.
- Parkinson's Research Outreach Network at the University of Hertfordshire – **PRONET** at **UH**.
- Recruit volunteers with specific expertise to help with the network.
- Funding sources – National Lottery, drug companies, Tesco, Borough Councils, Parkinson's UK, Rotary Clubs.

Our comments, looking forward:

PARK-RING was originally proposed as an acronym for the network, the word 'Ring' evoking an image of a connected network. However, as several discussion groups noted, **PARK-RING** may be mistaken as referring to car parking, and indeed Google searches bring up a car parking app!

The name Parkinson's Research Outreach Network, acronym **PRONET**, was suggested after the Hampson Park meeting (thanks John M). Adding at the University of Hertfordshire gives the local connection, so the acronym becomes **PRONET** at **UH**. This was the most popular name in a poll at the online meeting. After a discussion of potential names, the steering group decided that the network will be called Parkinson's Research Outreach Network at the University of Hertfordshire, shortened version **PRONET** at **UH**.

We welcome volunteers to help with the organisation of the network, to assist with specific tasks or to join the steering group. A couple of people who have already put themselves forward will be invited to join the steering group.

We will investigate the various funding sources suggested and others to find out which pots of money the network is eligible to apply for. Further suggestions and expertise in fund raising are

welcome! We are looking for around £3,000 – £5,000 per year to pay for the hire of venues and refreshments at events, and so we can help with travel costs.



Hampson Park Community Centre, 4th May 2024. One of the workshops discussion groups.

Thank you to all who attended and contributed to the workshops!

We would like to thank Nada Yousif, Paul Moran, Abdul-Azim Hassan, Eva Lesovskaya, Daniel Fray, Christie Goodro, and Jonathan Garnett for helping at the workshops.

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Report written by Lucy Annett, on behalf of the Parkinson's Research Interest Network steering group: Lucy Annett, Rosie Brewis, Becki Hadley, Ruth Herman, Mahmoud Iravani, Paul Williams.

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