

# CLINICAL TRIALS FOR PARKINSON'S: A COMPANION GUIDE



Co-created by people living with Parkinson's for people with Parkinson's who are interested in clinical trials.



Who?

Partners in Research are the 'patient and public involvement' group for NRS Neuroprogressive and Dementia Network. Our clinical trial companion guide was developed by people with experience of Parkinson's in collaboration with researchers and healthcare professionals.

What?

A group of people with experience of Parkinson's within Partners in Research worked together online to think about how we can better support people with Parkinson's in clinical trials research. After an initial draft of this guide, we received funding from the NHS Lothian Charity Fund to hold an in-person event. We were joined by other people with experience of Parkinson's to refine our work and create an online and paper-based resource.

Why?

Our Partners in Research felt that some of the stresses associated with clinical trials research could be reduced by having more information at the start about the clinical trial journey. Two stressors that we were particularly keen to explore were reasons someone may not be eligible to take part, and reasons a trial may end early.

Many scientists around the world are getting close to finding, not only symptom alleviating treatments, but possibly even a cure. None of this work will lead to a drug you can take until enough trialling of those drugs has been done so I would really encourage anyone who does have Parkinson's to think about getting involved in these trials and helping us to find a cure. **Joanna Goodburn-** (family member)

## Safety and Data Integrity

If you are looking to help with research then please go for it. It has been a positive experience for me and everyone is really pleasant, informative and has been good after-care and benefits for person doing is help further research. **David Rigg** (person with Parkinson's)

### Are you a working on Parkinson's research?

Each month we invite researchers to present their work to the group. We encourage researchers to submit PPI input requests so that people with experience of Parkinson's can help shape research that impacts them.

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I feel it is very important for people to get help and advice from in particular someone who has had experience. I hope this companion guide and research means people can share their experiences and remember the things that have inspired them rather than go the opposite way. **Henry Muchamore** (person with Parkinson's)

I enjoy the experience of clinical trials – some bits were tedious. It's of benefit to others in the future. Good to find a group of other people with Parkinson's, then you learn a lot about it from others. – **Alan Miller** (person with Parkinson's)



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Meet others with lived experience

Give researchers feedback on their work

Create research together

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