Exploring and Understanding the Scope and value of the Parkinson’s nurse in the UK (The USP Project)

Participant information sheet

You are being invited to take part in an online survey for the above study. The study is supported by funding from Parkinson’s UK. Before you decide whether or not to take part, it is important that you understand why the study is being carried out and what taking part will involve. Reading through this leaflet and discussing it with others, if you wish, will help you decide whether or not you would like to take part. Please contact the research team at Northumbria University if you would like to ask any questions or find out more information about the study.

What is the aim of the survey?

The aim of the nurse survey is to capture the working lives of as many nurses as possible; it will explore areas such as role, working practices, case load, qualifications, experience and level of competence. The aim of the surveys for people with Parkinson’s and carers is to gain a better understanding of the role of the specialist nurse and the impact they have.

Why have I been invited to take part?

As a specialist nurse, a person with Parkinson’s or a family member/carer of somebody living with Parkinson’s, your knowledge on appropriate care and support for people with Parkinson’s is hugely important and will contribute to an evidence base for the value and scope of Parkinson’s Nurses in the UK.

Do I have to take part?

No. It is entirely up to you whether or not you would like to take part. If you decide to take part in the survey, you may stop being involved at any time point, without giving a reason, but we will keep information about you that we already have.

What will participation involve?

If after reading this information sheet you decide you would like to take part, you can access the survey using the link on the study website. The survey should take between 15 and 45 minutes to complete, depending on your answers. You can provide your email address and return to complete the survey at another time, if you wish. At the end of the survey you will be asked if you would like to be contacted to discuss some of your answers. If you select yes, you will be asked to provide an email address.

Will my taking part in the study be kept confidential?

Yes, paper copies of your information will be kept in locked storage and electronic records stored in password protected folders. Small quotes of your own words may be used in study reports, publications or presentations. However, your name will not appear in any reports or documents resulting from this study and any information that could lead to you being identified will not be included. Any information that you were to share that suggests that you or others are at risk of harm may have to be disclosed.
How will my data be stored and how long will it be stored for?
All electronic data will be stored on a Northumbria University computer drive, which is password protected. All data will be stored in accordance with University guidelines and GDPR. Your information will be destroyed 5 years after the study is complete.

What are the benefits of taking part in the study?
Your views will help us to start to understand the type of support and health services that are most needed by people with Parkinson’s and their family members/carers.

What are the disadvantages of taking part in the study?
You will be asked to give up some of your time to complete the online survey.

How will we use information about you?
We will need to use information from you for this research project. This information will include your email address. We will only use this information to contact you about the study. People who do not need to know who you are will not be able to see your contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that nobody can work out that you took part in the study.

What will happen to the results of the survey and could personal data collected be used in future research?
Information provided by you and other people in the surveys will be analysed by the Research Fellow and will be written up and may be published in journal articles and presented at conferences. All data will be anonymised and you or the data you have provided will not be personally identifiable. We would be happy to provide you with a summary of the findings from the wider study if you wish.

Who is Organising and Funding the Study?
Northumbria University is organising this study with funding provided from Parkinson’s UK.

Who has reviewed this study?
Permission has been granted from Northumbria University’s Research Ethics Committee and Cambridge Central’s NRES Committee. They have reviewed the plans for how the study would be carried out in order to protect your interests.

What are my rights as a participant in this survey?
Northumbria University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the
General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner’s Office, please visit www.ico.org.uk Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - Duncan James dp.officer@northumbria.ac.uk

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to dp.officer@northumbria.ac.uk

Thank you

Contact for further information:
Dr Sarah Brown
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Tel: 0191 243 7502

PALS/complaints process for people with Parkinson’s/carers

If you prefer to raise your concerns with someone not involved in your care, you can contact the Patient Advise and Liaison Service (PALS). This service is confidential and can be contacted on Freephone:

Freepost PALS
Tel: 0800 032 0202
Text: 01670 511 098
Email: northoftynepals@northumbria.nhs.uk 0800 032 0202
Alternatively, if you wish to make a formal complaint you can contact the Patient Relations Department through any of the details below:

**North Tyneside:**
North East NHS Independent Complaints Advocacy (ICA)
Aidan House
Sunderland Road
Gateshead
NE8 3HU
Tel: 0808 802 3000
Email: ica@carersfederation.co.uk
Website: www.nenhscareplansadvocacy.co.uk

**Northumberland:**
Northumberland Independent Advocacy Service (NIAS)
Adapt (North East)
Burn Lane
Hexham
Northumberland
NE46 3HN
Tel: 01434 600 599
Email: generaloffice@adapt-tynedale.org.uk
Website: www.adapt-ne.org.uk