

## [Excellence Network projects awarded grants in 2023](#)

**“Start right; stay well”:** a screening tool that ensures that people with Parkinson's Disease have safe and timely nutrition, hydration and medication when acutely unwell.  
*Buckinghamshire Healthcare NHS Trust (BHT)*

Justine Greene, a specialist Speech and Language therapist (SLT) at BHT, aims to develop and pilot a swallow screening tool for the assessment of people with Parkinson's in acute settings. A review of current literature highlighted the lack of validated tools for use in the acute setting with non-stroke patients. The tool will be designed to rapidly identify people with swallowing difficulties within the first few hours of admission to reduce the risks associated with the poor management of dysphagia. The tool will be developed through a Model for Improvement Framework using PDSA (Plan Do Study Act) cycles, with support from the BHT Quality Improvement team. A pharmacist has been included in the project team given the association between dysphagia and access to time critical medications. The hope is that the new tool can easily be picked up by other trusts and health boards. A training programme has been incorporated into the project to raise awareness of dysphagia in people with Parkinson's, an often under-recognised symptom among patients and professionals alike. The local Parkinson's UK group is very supportive of the project and will be involved throughout to maximise the impact of the project.

**Improving the assessment and management of bladder symptoms in people with Parkinson's and related conditions: developing a bladder toolkit.**  
*University of Bristol*

Dr Emily Henderson, Dr. Matthew Smith and the team at University of Bristol are collaborating with the Royal United Hospitals Bath NHS Foundation Trust to develop a toolkit for the management of bladder symptoms amongst people with Parkinson's. This toolkit will be developed in consultation with multidisciplinary experts for use by healthcare professionals who are not urology specialists, enabling them to identify and treat bladder symptoms in a timely manner.

Bladder symptoms affect at least 50% of people with Parkinson's, but these are often overlooked in clinical settings and they can be stigmatising for them. Hence, in tandem with the toolkit, the team will also co-produce resources with and for people with Parkinson's to help them understand their symptoms and initiate timely self-management.

Once developed, the toolkit and resources will be widely available to benefit the Parkinson's community across the nation.

**Improving Healthcare Quality in Parkinson's: Preventive Approaches for Better Bone Health.**

***University of Glasgow***

Prof. Donald Grosset from the University of Glasgow will be undertaking a large UK database analysis to assess the prevalence of hip and bone fractures in people with Parkinson's in order to determine the current use of bone health management best practice. With double the risk of fractures amongst people with Parkinson's compared to the rest of the population and only 60% of them having their bone health assessed, this analysis aims to define the magnitude of the problem to inform the clinical community, as well as healthcare commissioners of the need of incorporating preventative bone health assessment into routine clinical practice for everyone with Parkinson's. Besides the national impact of the project, Prof. Grosset will be closely linking with 73 services across the UK who are enrolled in the Excellence Network's national Bone Health Service Improvement project to define the problem regionally. The inclusion of deprivation indices in the analysis will also highlight potential socioeconomic differences in fracture prevention which have an impact on underrepresented groups.

**A quality improvement project to identify, assess and address unmet needs of people with advanced Parkinson's disease in North Cumbria.**

***North Cumbria Integrated Care NHS Foundation Trust (NCIC)***

Dr. Ailish O'Callaghan, Dr. Rosanna Varden and the team at North Cumbria Integrated Care NHS Foundation Trust aim to identify those people with Parkinson's within the remotest parts of their region and those living with advanced Parkinson's who have difficulty accessing care. Besides identifying the number of those with limited to no access to services, the project also aims to identify the barriers to accessing care. The project team will further collect comprehensive data on the specific requirements and preferences of those with advanced care needs. The findings aim to inform a proposed sustainable pathway to holistic care for people with limited access to services within the region.

**Provision of Newly Diagnosed Exercise and Education Sessions.**

***NHSGGC, Regional Services Neurology.***

Specialist Physiotherapist, Fiona Turnbull aims to support young-onset people with Parkinson's who are newly diagnosed through education and exercise. Aiming to address inequalities in service provision within Glasgow's neurology services, the project proposes

to provide weekly group-based exercise and multidisciplinary education sessions. Co-production activities with the Parkinson's community have defined the nature of the sessions. Besides improving knowledge, balance and strength, these classes also aim to improve self-efficacy, self - management and quality of life for people with Parkinson's.

**Advance therapies in Parkinson's (ATPD) Pathway: an educational video guiding people with Parkinson's and their caregivers.**

***King's College Hospital***

Professor Kallol Ray Chaudhuri, Dr. Mubasher Qamar and the team at King's College Hospital will be developing an information and education video on Advanced Care Therapies in Parkinson's. With the goal of empowering people with Parkinson's within their service to better understand the complexities of treatment options for advanced the, the video will focus on the types of therapies available, the referral mechanisms and the scope and impact of these therapies. With the involvement of Parkinson's firmly in place in creating the blueprint of the video through the King's Patient and Public Involvement (PPI) group, the video will showcase the accounts and expertise of a range of clinical and allied health professionals.

**Introduction of a Parkinson's Champion Role for NHS Staff.**

***University Hospitals Plymouth NHS Trust.***

Parkinson's specialist Robert Davies and his colleagues at Derriford Hospital are developing and introducing Parkinson's Champions roles across the local NHS Trust, to address the inequity of care expected in acute settings. To improve the standards of care, the role will aim to reduce the number of medication errors that occur at the time of hospital admissions and the length of stay by increasing staff awareness about the condition. Through the provision of an ongoing support and education programme and development of resources for the clinical staff recruited to the role, the Parkinson's Champions will be able to address the anxieties and significant issues people with Parkinson's face during their admissions and appointments, thus offering them better support and empowering them. The resources and impact of the project will be widely shared across other Trusts. The project team have secured support from the University Hospitals of Plymouth Trust leadership which will ensure sustainability of the project.

**Ensuring sustainability of an online Parkinson's disease research register: Join Parkinson's Research (JPR).**

***Newcastle upon Tyne Hospitals NHS Foundation Trust***

Researchers and clinicians from the University of Plymouth and the Newcastle upon Tyne Hospitals NHS Foundation Trust led by Prof. Camille Carroll are creating a platform called JPR@Research+Me by merging two existing platforms Join Parkinson's Research (JPR) and Research+Me (an NHS owned platform). JPR@Research+Me will be an online register designed to connect people with Parkinson's to research projects in their local area, and will have functionality for healthcare and research professionals as well as people with Parkinson's. Besides encouraging services to play a larger role beyond clinical care to improve access to research opportunities for people with Parkinson's, this online register will also encourage greater participation in research, leading to better healthcare outcomes for people with Parkinson's and resulting in more efficient, complete, inclusive and representative trials.

### **Introducing and Evaluating the use of Home Postural Blood Pressure Monitoring in People with Parkinson's.**

***University of Bristol***

Dr. Katherine Lloyd from the Ageing and Movement Research Group from the University of Bristol is collaborating with Emily Henderson from the Royal United Hospitals Bath NHS Foundation Trust and Victoria Haunton from the University of Plymouth to improve how Orthostatic Hypotension (OH) is evaluated and managed by people with Parkinson's by using home blood pressure (BP) monitoring. OH which causes BP to drop on standing upright, causes lightheadedness, fatigue, weakness and loss of balance is seen in 30-50% of people with Parkinson's, increasing the risk of falls amongst them. As BP is variable and annual reviews don't offer a true representation of this variance, the project team have planned to loan BP monitors to people with Parkinson's so they may record their readings at home at regular intervals. Through robust quality improvement methodology, using a Model for Improvement Framework that uses the PDSA (Plan Do Study Act) evaluation, the team will evaluate the acceptability, feasibility, sensitivity and impact of home-based BP monitoring to establish whether it alters management of OH.

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### **Aligning management of bone health in Parkinson's with the new 2021 The National Osteoporosis Guideline Group (NOGG) guideline.**

***University of Bristol***

The Ageing and Movement Research Group from the University of Bristol are updating the BONE-PARK algorithm to reflect the most recent research in bone health management and thus improve bone health for people with Parkinson's across the UK. Dr. Emily Henderson and her collaborators Veronica Lyell, Michael O Breasail and Celia Gregson will be

undertaking this work. The project promises to provide current and standardised risk assessment protocols and treatment recommendations for improved bone health management along with supporting greater awareness/a bigger call to action among multidisciplinary clinicians through the revised algorithm. People with Parkinson's have helped shape this project and will further be involved in co-producing educational materials in various formats to support a diverse and representative Parkinson's community to make better decisions about their bone health.

**Developing and expanding a palliative care service for people living with the impact of Parkinson's disease, in Bristol, South Gloucestershire and North Somerset.**

***North Bristol NHS Trust***

Dr Ed Richfield and his colleagues from North Bristol Trust (Emma Straton) and St. Peter Hospice (Bethany Wright and Caroline Mundy) are developing and expanding the multidisciplinary palliative care service for people living with the impact of Parkinson's within this region. Integrated palliative care models for Parkinson's are lacking compared to other neurodegenerative conditions, and this project has proposed to create a sustainable model which will address this unmet need and provide equitable and timely access to those who most require it. Psycho-social support and communication support are two key areas which the clinic is introducing in this offer. The project proposes support for not just people with Parkinson's but also their carers and loved ones. This model will be commissioned for the region at the end of the project and is highly likely to influence national practice.

**Redeveloping PD MedCalc.**

***Wansbeck General Hospital, Northumbria Healthcare NHS Trust***

Dr. James Fisher from the Wansbeck General Hospital (Northumbria Healthcare NHS Foundation Trust) and his collaborators at Manifesto Digital have undertaken the redevelopment and redesign of PD MedCalc to improve the safety, user interface and usability to current treatment standards. PD MedCalc is an online medication calculator that assists with the conversion of a patient's Parkinson's medication to non-oral form. Dr Fisher will also apply to register the tool as a medical device with the Medicines and Healthcare products Regulatory Agency (MHRA) upon completion of the redesign.

**To run Exercise and Education Sessions for the Newly Diagnosed Parkinson's patients within 6/12 months of their diagnosis to attend once a week for 10 weeks.**

***Isle of Wight NHS Trust***

Physiotherapist Rebecca Verling aims to support people with Parkinson's who are newly diagnosed through a group-based education and exercise programme within 6 to 12 months of their diagnosis through this project. After a successful pilot, the project is now extending the service to a newer patient base and continues to apply quality improvement

methodology to the project to make it sustainable and replicable in collaboration with the Excellence Network service improvement team. The project is likely to encourage self-management and enhance knowledge of the condition while impacting Activities of Daily Living and functional mobility. It will also test a cost-effective way of offering support to those newly diagnosed through a group based approach which might reduce waiting times to being seen by AHCPs. Given the geography of the project, it is highly likely to tackle health inequalities.

**An exploration of service users' perceptions of the Parkinson's Beat Programme.  
*Robert Gordon University, Aberdeen***

Dr. Julie Jones in collaboration with Dr. Yoon Irons (University of Derby) have partnered with two people with Parkinson's, Jo Holland and Allison Williams to evaluate service user perceptions of the Parkinson's Beats programme. This is a novel and exciting cardio drumming exercise programme that incorporates drumming a large ball with sticks along with the beats of music. The routine targets flexibility, balance and strength training and the addition of music results in added benefits relating to mood and well-being. The project will further measure the impact of the exercise routine on quality of life, balance and functional mobility.

*Please note that this type of project would now fall out of the remit of the Excellence Network Project Grants Scheme, which was revised in 2023.*