

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.