

Excellence Network projects awarded grants in 2024

Developing a collaborative Movement, Voice and Swallow Prehab Programme for people with Early Parkinson's from Cardiff and The Vale of Glamorgan Cardiff and Vale University Health Board (CAVUHB)

The Physiotherapy and Speech and Language Therapy outpatient departments at CAVUHB, led by Annabelle Price at Cardiff and Vale of Glamorgan are pioneering a collaborative programme aimed at people newly diagnosed with Parkinson's within 6 months of diagnosis.

Within a quality improvement framework and informed by the priorities of people with Parkinson's, the initiative will focus on providing early intervention and vital information on how the condition affects movement, clarity of speech, vocal loudness, and swallowing abilities. Through an integrated group-based programme, it will offer specially designed exercises to maintain functionality while encouraging the integration of these exercises into daily routines, and fostering the creation of supportive peer networks.

Additionally, the programme aims to facilitate easier access to local opportunities, encouraging prolonged self-management and reducing pressures on outpatient services, thus making a sustained impact further along the pathway.

At the end of the grant duration, the programme will be integrated into CAVHUB's LiveWell Rehabilitation strategy by demonstrating that this collaborative approach, delivered by specialised staff, not only improves patient outcomes but also offers a greater social return on investment compared to existing siloed models.

Maximising functionality and accessibility of an online Parkinson's disease research register: Join Parkinson's Research (JPR)

Newcastle University, Clinical Ageing Research Unit

Dr. Camille Carroll and Dr. Marie-Louise Zeissler, along with their teams at University of Plymouth, and in collaboration with teams at Newcastle upon Tyne Hospitals NHS Foundation Trust and University College London have been awarded funding to continue the work to create JPR, a web-based UK research registry platform for Parkinson's trials, which will connect researchers and people with Parkinson's (pwP) by allowing pwPs to express interest in studies and allowing study sites to directly contact them.

Following the development of the JPR@Research+Me platform through a [small project grant in 2023](#), the team now propose to develop a bespoke dashboard, which will enable the platform to have functionality to implement and track, not only recruitment and successful recruitment strategies, but also significantly report on recruitment across various demographics, helping to make research more inclusive and representative.

During the course of the grant, the registry will be optimised and launched as a proof of concept within the Edmund J. Safra Accelerating Clinical Trials in Parkinson's disease (EJS ACT-PD) study to evaluate its usability.

Given that less than 5% of pwPs within the UK participate in research, the ultimate aim of the project team, to launch the platform as a national clinical PD research recruitment tool to encourage greater participation in research, will lead to better healthcare outcomes for people with Parkinson's

Establishing a swallowing assessment and rehabilitation programme for people with Parkinson's disease (pwPD) incorporating FEES, EMST and traditional swallow rehabilitation

Bromley Healthcare

With a focus to preempt swallowing impairments and prioritise rehabilitation amongst people with Parkinson's (pwP), Speech and Language Therapy Service Lead at Bromley Healthcare, Bindu Vekaria, proposes to provide a proactive comprehensive swallow rehabilitation Parkinson's service pathway that will incorporate swallowing assessments through Flexible Endoscopic Evaluation of

Swallowing (FEES), followed by the NICE recommended Expiratory muscle strength training (EMST) rehabilitative treatment.

The dissemination plan proposed, critically aims to highlight the need for adoption of recommended Speech and Language Therapy (SLT) resources and encourage appropriate commissioning and funding of services; the outcomes emerging out of this project will be shaped into an standard operating procedure (SOP) to provide a blueprint for replication and scalability for other services, and will also include contributions to the Royal College of Speech and Language Therapist (RCSLT) guidelines on managing swallowing issues in pWP, influencing and encouraging standardised national practice.

How does the Telea voice therapy app benefit an NHS Parkinson's clinic? Derbyshire Community Health Services (DCHS), University Hospitals of Derby and Burton (UHDB)

Specialist Speech and Language Therapist, Caroline Bartliff, at DCHS has teamed up with Telea, the digital health private company that has developed the Telea voice therapy app, to offer the app to people with Parkinson's within their multidisciplinary service pathway with the aim to improve access to voice therapy by decreasing wait times, enabling home practice, and facilitating engagement in therapy by personalising content.

In a pilot done recently with people with neurological conditions at UHDB, the use of the app demonstrated a reduction in wait times for interventions, reduced need for face to face input, remote monitoring and feedback between therapists and clients, and better clinical outcomes for the users.

Encouraged by these promising results, the project team will further evaluate the use of Telea for people with Parkinson's in line with NHS long term plan for digital transformation, in order to establish the cost-effectiveness and time-saving capacity of using the app and make a case for future investment. The outcomes of the project will be shared nationally.

Translation of the "My Parkinson's" web application into Welsh Cardiff and Vale University Health Board (CVUHB)

Consultant physicians at CVUHB, Sarah Page and Biju Mohammed, have been awarded funding to develop a Welsh language version of the [My Parkinson's app](#), an existing web application that was created by them in collaboration with

multidisciplinary experts and people with Parkinson's in Cardiff and Vale of Glamorgan.

This app, which provides information about Parkinson's and common symptoms to those newly diagnosed, was designed to be a postdiagnostic counselling tool to promote self management strategies where appropriate. By creating a Welsh language version of the app, it will comply with Welsh language legislation for public sector resources, enabling the team to make the app available to other health boards and services in Wales and ensuring Welsh language users have equitable access to the resource. As with the development of the English language version of the app, the team will be co-producing the Welsh version with local Welsh speaking members of the Parkinson's community.

‘Connect and Conquer’: Optimising Physical Self-management in Parkinson's Cornwall Partnership NHS Foundation Trust (CFT)

Specialist Physiotherapist Sophia Hulbert and a team at CFT are partnering with the local authority Active Cornwall, Cornwall County Council to improve their award winning programme, 'Connect and Conquer' (CC), which has been providing people with Parkinson's the opportunity to establish a highly active lifestyle and work towards self-management of their condition across Cornwall since 2019 and has been replicated in other NHS trusts.

With the aim of the current project being to improve the programme to provide ongoing support to encourage long-term behaviour change, the team will be evaluating the impact of the current programme on self-management, what long-term self-management looks like, and how this can be offered through a co-designed and co-delivered upgraded CC programme that adopts a multidisciplinary approach. The highlight of the project is the collaborative approach working across health, social and charitable sectors which offers opportunity for an innovative, joined up approach to building sustainable services, learnings which promise to have a national impact.

Enhancing Parkinson's Care: Speech Therapy Education and Rehabilitation Sessions.

Hertfordshire Community NHS Trust (HCT)

The Speech and Language Therapy team at HCT comprising Veronica Clarke and Clare Ramsay aim to address long waiting times within their service, offer timely

patient-centred intervention and evidence-based treatment, improve clinical outcomes, and reduce health inequalities in Parkinson's care within the speech service at Hertfordshire through a group-based approach.

They propose the Parkinson's Education and Training Session (PETS) focused on speech, language, and swallowing, delivered in a group setting, alongside a structured six-week group rehabilitation program targeting speech and swallowing difficulties; interventions which will be designed to empower pwP and their carers with knowledge and tools for managing the condition. The methodology includes improving the triage process, co-production with pwPs, and measuring impact through Patient-Reported Outcome Measures, Therapy Outcome Measures, and SLT screening measures, feeding into an audit cycle for continuous service improvement with the aim to incorporate the restructured pathway into current practice. Best practice, including the audit outcomes, will be shared nationally.

Introduction of EMST to Adult Community SLT Parkinson's service provision in Berkshire.

Berkshire Healthcare Foundation Trust (BHFT)

The SLT (speech and language therapy team) at BHFT led by Alison Attenborough have been awarded funding to address the gap in service provision of Expiratory Muscle Strength Training (EMST) as an intervention for those people with Parkinson's (pwP) presenting with dysphagia.

Currently, the service can only offer EMST to those who can self-fund, potentially exacerbating health inequalities for those who cannot afford it. The project's objectives over two years include ensuring equity of access to EMST devices, improving dysphagia care quality, determining resource allocation for future use, and developing a Standard Operating Procedure (SOP) for EMST integration into long-term Parkinson's care pathways.

The project team seeks to bridge the gap between current practice and NICE guidelines, improving clinical outcomes amongst pwPs and service outcomes such as reduction in hospital admissions due to aspiration pneumonia - learnings which will be shared to influence national practice on dysphagia management.

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“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.

[Read about the completed project outcomes here.](#)

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 and 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.

[Read about the completed project outcomes here.](#)

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.

[Read about the completed project outcomes here.](#)