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Putting the person at the centre: applied research in Parkinson's and related conditions

The policy challenge

People living with Parkinson's and related conditions, and the organisations that advocate on their behalf, have been calling on the government to address what they consider to be systemic failings in care provision. The Parky Charter petition calling for action to improve the lives of people with Parkinson's was submitted in 2024. An updated version followed in 2025 emphasising the need for timely diagnosis, comprehensive care and dignity for all people with Parkinson's.

Research offers one route to improving care provision. A Government response to the updated Parky Charter petition, issued on 29th April 2025, explained that the Government spent £79.06 million on Parkinson's research between 2019 and 2024. Despite this substantial investment, why do people continue to feel let down and poorly supported? We looked in more detail at what research is funded and what evidence researchers produce.

Background: the scope of applied research

Parkinson's research covers a broad spectrum. This ranges from understanding mechanisms underlying disease-related changes in the brain to sensitive provision of care at the end of life. Scientific research aimed at identifying a cure or developing effective symptomatic treatments for Parkinson's and related conditions is vital. Alongside this, research should help ensure that people who are living with Parkinson's today receive good care and support following a timely diagnosis. This is called applied research.

Applied research with people and service systems focuses on diagnosis, treatment and care, exploring ways of improving patient experience. Here, we also included primary prevention – understanding the personal, environmental and lifestyle factors that could prevent people developing Parkinson's or delay its onset.

What we did

We asked:

- What proportion of Parkinson's research funding awarded in the UK over the last five years supports applied research on primary prevention, diagnosis, treatment and care?
- How much of the evidence published by Parkinson's researchers around the world in the last ten years reflects applied research and has potential to directly affect patient experience and improve care?

What we found: Funding for applied research in Parkinson's

We studied 670 research grants reflecting an investment of £280 million awarded for UK-based Parkinson's research between 2014 and 2024. Around one quarter of these were for applied research. Nearly 9 out of 10 applied research grants focused on treatment or diagnosis. Few focused on care and hardly any on primary prevention.

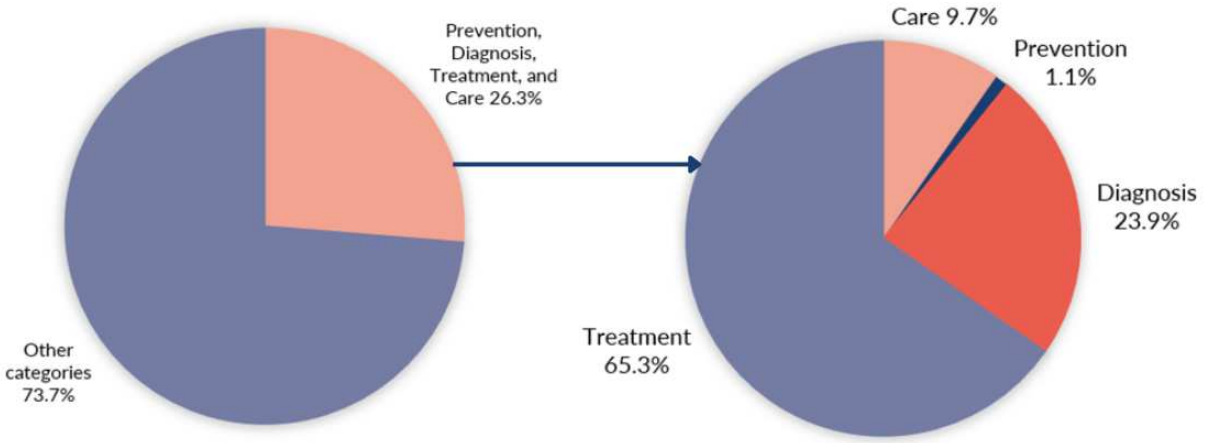

Figure 1. Distribution of funding allocation across categories: including all categories (left) and restricted to the four applied research categories only (right)

Funding was highly concentrated in institutions located in London, Oxford and Cambridge, and male researchers received nearly three-quarters of all applied research funding.

What we found: Applied research evidence in Parkinson's

We studied over 30,000 journal articles published between 2019 and 2024 reporting research studies and systematic reviews. Of these, just under one-third reported on applied research topics. Treatment and diagnosis accounted for nearly 9 out of 10 of the research studies. There was limited focus on care or primary prevention.

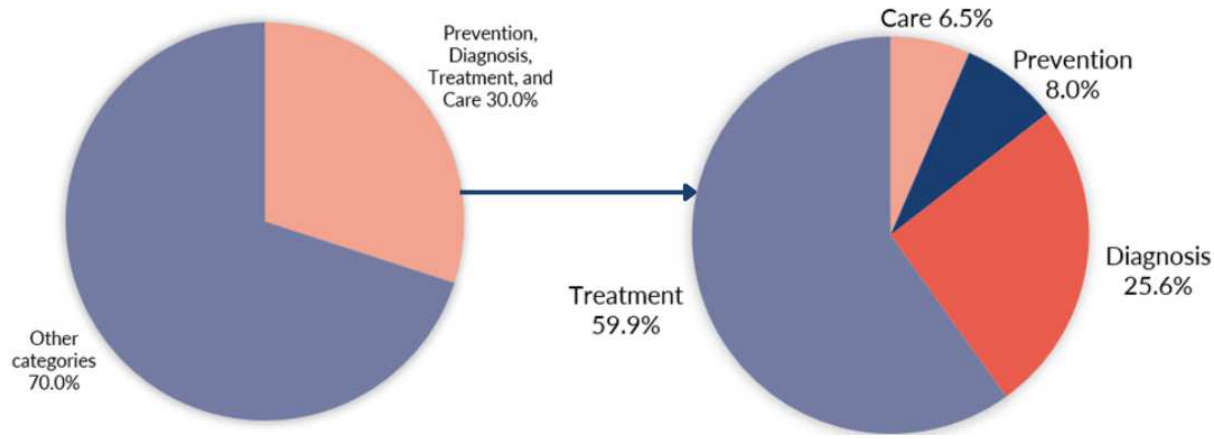

Figure 2. Distribution of research evidence across categories: including all categories (left) and restricted to the four applied research categories only (right)

What was the main focus of research in each applied category?

Prevention: whether having other health conditions, receiving medical treatments, lifestyle choices or environmental exposures were linked to the risk of developing Parkinson's

Diagnosis: identifying techniques for improving accuracy and timeliness of diagnosis

Treatment: pharmacological therapies, more specifically optimising existing treatments, and addressing motor symptoms

Care: healthcare provision and community and family support

What are the gaps and limitations in Parkinson's applied research?

- Patient experience is rarely considered, and the human perspective is often missing.
- While motor symptoms receive a lot of attention, there is little research on other commonly experienced symptoms such as anxiety, depression, cognitive impairment, fatigue, pain and communication difficulties, even though these are priorities for people living with Parkinson's.
- Most research is descriptive, with relatively few studies testing or implementing approaches or interventions that could improve services and enhance patient experience.
- Research on dementia with Lewy bodies and other rarer Parkinsonian conditions is limited.
- Few studies directly address health inequalities.

Policy implications

Applied research on Parkinson's disease and related conditions needs a radical change of emphasis, centred on the person with Parkinson's (or a related condition). Applied research must:

Address the priorities of people affected and their unpaid carers

Serve the overall goal of enabling people to live as well as possible with the condition

Provide the evidence base for services to offer compassionate and effective support across the pathway from pre-diagnosis to end of life

What can funders do to strengthen applied research in Parkinson's?

To improve the situation, funders can:

- Strengthen research in prevention and care, with greater emphasis on intervention and implementation studies.
- Increase the focus on non-motor symptoms, psychological health, rehabilitation and improving patient experience.
- Involve people with lived experience of Parkinson's in prioritising topics and making funding decisions.
- Embed health inequalities firmly within study design and commissioning.
- Address evidence gaps for dementia with Lewy bodies and rarer Parkinsonian conditions.
- Support geographically diverse and interdisciplinary research capacity.

Conclusions: Delivering greater value from applied research

A more coordinated, person-centred applied research strategy across government and charitable funders could deliver greater public value from future investment and improve outcomes and experiences for people living with Parkinson's and related conditions.

Acknowledgements

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Contact details and where to find out more

Read the full policy report: Clare, L., Martyr, A., Oyebode, J., Prina, M., Windle, K., Quinn, C., Caulfield, M., Gamble, L., Adams, E., & Charlwood, C. (2026). Applied research in Parkinson's disease and related conditions: mapping the funding and evidence landscape. NIHR Dementia and Neurodegeneration Policy Research Unit, University of Exeter.

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