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Applied research in Parkinson's disease and related conditions: mapping the funding and evidence landscape

Report

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Applied research in Parkinson’s disease and related conditions: mapping the funding and evidence landscape

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The Technical Appendix provides further details and can be accessed here:
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Summary

Why this report matters
Parkinson's disease and related Parkinsonian conditions pose a growing challenge for health and care systems in the UK. These conditions are progressive and life-limiting. Treatments remain largely symptomatic, and there is still no proven disease-modifying therapy. People affected report unmet needs across diagnosis, treatment, care and support. This report was commissioned to inform policy and research commissioning by examining whether current research funding and evidence align with applied needs. It maps UK research funding since 2014 and international research evidence since 2019 across applied research categories of prevention, diagnosis, treatment and care, with health inequalities considered throughout.

What we did
We analysed the 670 UK-based research grants awarded since 2014, representing around £280 million in investment. We mapped 9,196 applied research papers and systematic reviews published internationally between 2019 and 2024. Funding and evidence were categorised into prevention, diagnosis, treatment and care.

What we found
Applied research is relatively under-represented. Nearly two-thirds of UK Parkinson's research funding supports disease mechanisms and pre-clinical research. Only around one-quarter is directed towards applied research.
Funding within applied research is uneven. Treatment dominates, accounting for around two-thirds of applied research grants and nearly a quarter of applied research funding. Diagnosis receives a smaller but substantial share. Care attracts limited funding, and primary prevention is almost entirely absent, receiving just 1.1% of total applied research investment.
The research evidence broadly reflects the same patterns. Most applied studies focus on treatment, particularly drug therapies and motor symptoms. There is far less evidence on prevention and care, and limited attention to common symptoms such as anxiety, depression, cognitive impairment, fatigue, pain and communication.
Prevention is a critical gap. Although many studies examine factors associated with Parkinson's risk, almost none test approaches or interventions designed to reduce risk or delay onset. The relatively high number of reviews in this area reflects growing interest and suggests there may be potential to increase capacity for prevention research.
Care research is under-developed. Much of the care literature is descriptive, with very few intervention studies, limiting the evidence available to support service development and delivery. Palliative and end-of-life care are particularly under-researched.
Inequalities and capacity issues persist. Very few grants or studies explicitly consider health inequalities beyond age and sex, limiting insight into differential needs and outcomes. Funding is also geographically concentrated, with over half awarded to institutions in London and Oxbridge, raising questions about regional research capacity and equity.

What this means for policy and funders
Overall, there is a mismatch between applied research needs and the current portfolio. There is potential to increase the focus on prevention and care, strengthen research on non-motor symptoms and lived experience, embed inequalities as a core design consideration, and support more geographically and disciplinarily diverse research teams. A more coordinated, person-centred applied research strategy, developed with involvement of people with lived experience, has the potential to deliver greater value from future investment and improve outcomes for people affected by Parkinson's and related conditions.

Executive Summary

Background
Parkinson's disease and related Parkinsonian conditions are becoming increasingly prevalent in the UK as our population ages, placing growing demands on health and care systems. These conditions are progressive and associated with a wide range of motor and non-motor symptoms, cognitive impairment and complex care needs. While significant advances have been made in understanding disease mechanisms, treatments remain largely symptomatic and people affected continue to report substantial unmet needs across the disease course.

The Department of Health and Social Care commissioned the NIHR Policy Research Unit in Dementia and Neurodegeneration at the University of Exeter (DeNPRU Exeter), working in partnership with Parkinson's UK, to map the current Parkinson's applied research funding and evidence landscape. The purpose was to assess the relative distribution of applied research funding and outputs across primary prevention, diagnosis, treatment and care, including end-of-life care, to consider how this relates to the priorities of people living with the condition, and to identify gaps that are relevant to future research commissioning by government and charitable funders. This report combines an analysis of UK research funding with an international mapping of the applied research evidence base.

Methods
We identified UK-based research grants awarded since 1 January 2014 using the Dimensions.ai database and the Michael J Fox Foundation website. We included 670 grants representing approximately £280 million in total investment. We initially categorised grants into seven broad domains, with detailed analysis focusing on the four which captured applied research: prevention, diagnosis, treatment and care. Extracted data included funding amounts, funders, study focus, conditions addressed, geographic location of host institutions and characteristics of lead investigators.

A comprehensive search of the PubMed database identified research literature published between January 2019 and October 2024. Following screening of over 60.000 records, we included 9,196 applied research articles (primary studies and systematic reviews). These were categorised using the same four applied research domains as the funding analysis.

Across both datasets, we examined health inequalities based on explicit mention in titles or abstracts.

Key findings: research funding
The UK Parkinson's research funding landscape is characterised by strong investment in disease mechanisms and pre-clinical research, which together account for nearly 58% of total funding. Applied research addressing primary prevention, diagnosis, treatment or care directly accounts for only around one-quarter of grants and funding. While foundational research is essential for long-term progress, this balance has implications for the generation of evidence that can inform near-term policy, practice and service delivery. Within applied research, funding is highly uneven:

- Treatment dominates, accounting for approximately 65% of applied research grants and nearly a quarter of total applied research funding.
- Diagnosis receives a smaller but substantial share of applied research investment.
- Care accounts for less than 10% of applied research grants and around 4% of total applied research funding.
- Prevention is almost entirely absent, with only two grants identified, representing around 1.1% of total applied research funding.

This distribution indicates limited investment in research aimed at reducing risk, delaying onset, improving care pathways, or supporting people to live well with the condition.

Most applied research funding (over 90%) focuses on Parkinson's disease. Dementia with Lewy bodies (DLB) and rarer Parkinsonian conditions such as Progressive Supranuclear Palsy, Multiple System

Atrophy and Cortico-Basal Degeneration receive very limited attention, despite significant unmet clinical and care needs.

Only a small number of grants explicitly address health inequalities. Where inequalities are mentioned, they most commonly relate to age and sex. Limited attention is paid to socio-economic status, ethnicity, geography, disability or caring responsibilities, restricting the usefulness of the evidence for targeting interventions or reducing unequal outcomes.

Funding is also geographically concentrated. Over half of all applied research funding is awarded to institutions in London and Oxbridge, with relatively limited investment in other regions. This concentration raises questions about research capacity, regional equity and opportunities for wider engagement.

Key findings: research evidence

Of more than 60,000 research records screened, only around 15% (9,196) were classified as applied research. The remaining literature focused on disease mechanisms or other non-applied areas. This pattern mirrors the funding landscape and suggests limited growth in evidence directly relevant to policy, commissioning and service delivery. Among applied research publications:

- Treatment accounts for nearly 60% of primary studies and over two-thirds of systematic reviews.
- Diagnosis represents around one-quarter of primary studies.
- Prevention and care each account for less than 7% of primary studies.

Prevention research is dominated by observational studies examining associations between potential risk factors and Parkinson’s. Almost no studies evaluate interventions designed to reduce risk or delay disease onset. Despite receiving minimal funding, a relatively high proportion of systematic reviews suggests growing interest and potential to build capacity through opportunities for targeted commissioning aligned with public health and risk-reduction objectives.

Research on diagnosis is technically advanced and focuses primarily on assessment accuracy, differential diagnosis, imaging, biomarkers and data-driven approaches. However, there is very little research on communication of diagnosis, patient experience, or real-world implementation within health and care systems. This limits the translation of technical advances into improved diagnostic pathways.

Treatment research is heavily weighted towards pharmacological therapies, deep brain stimulation and motor symptoms. Other common symptoms, psychological health, self-management and lifestyle-based interventions receive far less attention, particularly in later-phase trials. Much of the intervention research focuses on optimising existing medical treatments rather than developing disease-modifying therapies. Evidence for rarer Parkinsonian conditions is extremely limited.

Care research is predominantly descriptive, with relatively few intervention studies. Evidence on palliative and end-of-life care is sparse, particularly in relation to specific interventions, advance care planning, coordination of services and support for unpaid carers.

Health inequalities are infrequently addressed in the applied research literature. Fewer than 6% of primary studies and fewer than 4% of systematic reviews mention inequalities explicitly, most commonly age and sex. This constrains the ability of policymakers and funders to understand differential impacts and design equitable interventions.

Lived experience and stakeholder perspectives

Consultation with people with lived experience, carers, practitioners and other stakeholders highlighted concerns about the lack of prevention and care research, limited progress in treatment despite sustained investment, under-representation of rarer conditions, and insufficient attention to inequalities.

Implications for policy and research commissioning

This mapping exercise highlights a robust but imbalanced Parkinson's research landscape. For DHSC, NIHR and charitable funders, the findings point to opportunities to strengthen the contribution of applied research to policy goals, service improvement and population health.

A radical change of emphasis in applied research on Parkinson's disease and related conditions should start with placing the person with Parkinson's (or a related condition) at the centre and ensuring that applied research addresses the priorities of people affected and their unpaid carers, serves the overall goal of enabling people to live as well as possible with the condition, and provides a foundation for services to offer compassionate and effective support across the pathway from pre-diagnosis to end of life.

Key implications include the need to:

- 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 quality of life.
- Involve people with lived experience of Parkinson's in prioritising topics and making funding decisions.
- Embed health inequalities as a core consideration in study design and commissioning.
- Address evidence gaps for DLB and rarer Parkinsonian conditions.
- Support geographically diverse and interdisciplinary research capacity.

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

1 Background

Recent research by Parkinson's UK estimates there are around 162,360 people living with Parkinson's in the UK[1], and this is expected to rise to 173,000 by 2030. Up to 21,000 more may be living with the condition but undiagnosed. The number of people diagnosed with a related condition is also increasing; there are thought to be 9,400 people with Lewy body dementia (DLB), 2,570 with progressive supranuclear palsy (PSP), 1,780 with multiple system atrophy (MSA), and 800 with cortico-basal degeneration (CBD)[1]. These complex conditions are characterised by progressive loss of motor control along with a wide spectrum of non-motor symptoms and varying degrees of cognitive decline[2,3]. Currently available treatments are symptomatic and disease-modifying treatments are still awaited[4,5]. People living with these conditions need more effective treatments to help manage their symptoms and appropriate care, services, support and information[6]. Despite advances in research, significant gaps remain in applied and clinical research focused on understanding how to reduce risk or delay onset, make timely and accurate diagnoses, develop effective treatments, and provide care that meets the needs of people living with these conditions, including end-of-life care[6].

Allocating research funding in a way that addresses key needs and priorities is fundamental to addressing these gaps and reducing health inequalities. DHSC identified a need to better understand how well current research activity and research funding allocation maps onto these needs and reflects the priorities of those living with the condition, or those who support, care or advocate for them, and identify underfunded or unfunded areas that would benefit from investment. In response to this, DeNPRU Exeter was asked to map research funding allocation and research evidence in applied, clinical and patient-facing research using the overarching categories of prevention, diagnosis, treatment and care (including end of life care), with inequalities as a cross-cutting category, to identify and prioritise gaps in these areas and provide recommendations to guide research commissioning. The project was conducted in partnership with Parkinson's UK, and included consultation with people with lived experience and other stakeholders.

The primary aim of the project was to understand the way in which research funding is being used to support applied research and the nature of the evidence available from applied research, so that future funding can be directed to areas with the greatest need and best potential to improve outcomes. This is the full report from the project and builds on the two earlier interim reports[7,8].

As the grants and research evidence we proposed to examine covered the full spectrum of research from basic science to application, we first grouped the records into seven categories:

- Epidemiology and prevalence
- Disease mechanisms
- Phenomenology
- Prevention
- Diagnosis
- Treatment
- Care (including end-of-life care)

We then focused on the four categories of applied research, prevention, diagnosis, treatment and care, to provide a more fine-grained picture of research activity in these areas. Table 1 shows how we defined the scope of these areas. One caveat is that boundaries are not distinct and there can be overlap between the categories, but each record was coded only once and assigned to the best-fitting category.

Table 1. The four categories of applied research

Prevention	Focuses on primary prevention research aiming to identify lifestyle and environmental risk factors and inequalities that could potentially be ameliorated, and protective factors that could be augmented, and to implement and test programmes or interventions that could lead to reduced risk of developing the condition or to delayed onset. These could range from national-level policy change to interventions with individuals or groups.
Diagnosis	Is concerned with developing approaches that can improve the potential for accurate and timely diagnosis of the condition.
Treatment	Covers approaches to understanding, assessing, monitoring and treating or managing clinical symptoms arising as part of, or in relation to, the condition. These may be pharmacological or non-pharmacological. Research in this area develops ways to better understand the presentation of symptoms and their evolution over time, translate laboratory findings to clinical application, provide more effective treatments, and gather evidence about clinical and cost effectiveness of medications, technologies and therapies by applying them to and/or involving people who have the condition.
Care	Focuses on the experience of living with the condition or being a carer for someone living with the condition, on needs and support for living with the condition from diagnosis to end-of-life, and on care systems and pathways, organisation and provision of services, resource utilisation and costs.

We note that fundamental research outside the four categories of applied research provides a foundation for future translational and clinical work and may lead ultimately to prevention, improved treatment or a cure. However, for this project our remit was to focus on the applied end of the research spectrum.

2 The research funding landscape

What we did

We searched the Dimensions.ai database and the website of the Michael J. Fox Foundation (MJFF; a US-based charity that funds research in the UK) on 23rd August 2024 for details of relevant grants awarded for research conducted in the UK since 1st January 2014. We conducted searches for each of the conditions of interest – PD, DLB, PSP, MSA and CBD – and each title and abstract was screened for eligibility by two researchers working independently. Disagreements were resolved by discussion among the research team. For each eligible grant we extracted the title and abstract and recorded information about funding body, amount awarded, type of funding (e.g., project grant, fellowship), and study design (e.g. randomised controlled trial, cohort study). Where grants were awarded in currencies other than GBP, we converted amounts to GBP using exchange rates applicable at the start date of each grant, so that conversions reflected the value of the currency at the time the funding commenced. A detailed protocol is available in the Technical Appendix.

What we found

The search of Dimensions identified 26,015 records, of which 24,934 were awarded or begun before 2014 or were not UK-related, leaving 1,081 records for detailed screening. For duplicate entries arising where grants received joint funding from multiple bodies, funding extensions were granted, or the lead applicant changed, institution details were merged with the original entry. For joint funding and extensions, these amounts were added to the original award. Where institutions changed, the higher value was taken, and the new institution was used as the geographical location. Awards covering research networks or infrastructure not specific to Parkinsonian conditions, such as Biomedical Research Centres (BRCs), but where these conditions were mentioned among the topics that might be addressed (36 awards totalling £271,502,791) were also excluded. This yielded 562 records for inclusion, to which were added 108 records retrieved from a separate search of the Michael J Fox Foundation website. The final dataset therefore included 670 unique grants. For reporting purposes, we have aggregated the information across funders overall or by sector (government or charity).
The flowchart in Figure 1 summarises the search process and outcomes.

We first considered the number and relative proportion of research grants awarded in each of the seven categories plus an additional category for research infrastructure awards (Table 2). Overall, 176 (26.3%) grants awarded could be classified into one of our four categories of interest. The remaining 494 (73.7%) represented disease mechanism and pre-clinical studies, observational and experimental studies, epidemiological studies other than those included in one of the four main categories, and research network or infrastructure awards specifically focused on the relevant conditions.

Figure 1. Flowchart: grant funding

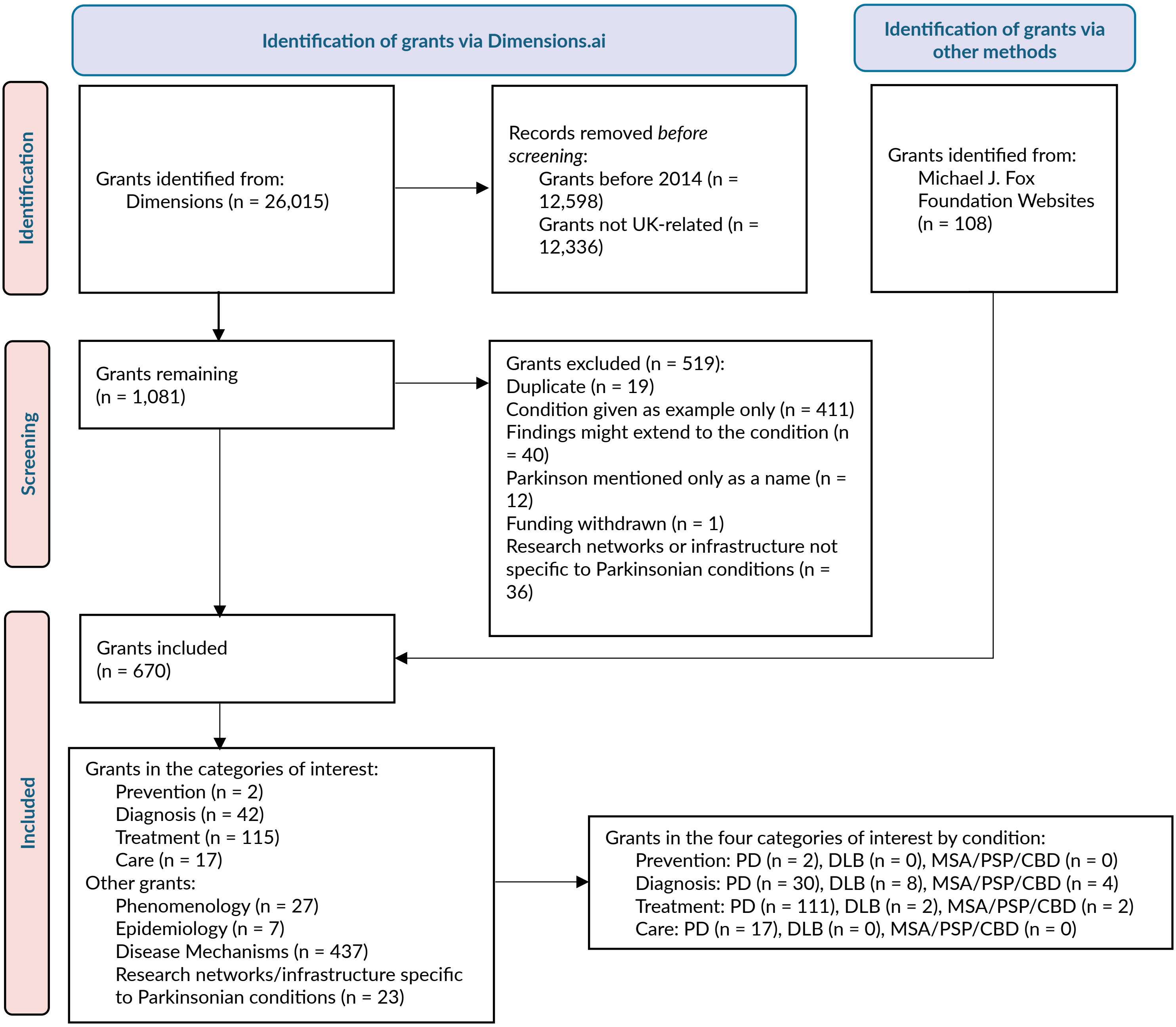


Table 2. Number of grants and funds invested across all categories showing how the overall total is divided among categories in order from greatest to least

Category	Grants*	Total funds awarded	% of total funds+
Overall total	670 (207)	£280,105,934	100%
Disease mechanisms	437 (167)	£162,191,932	57.9%
Treatment	115 (15)	£69,481,222	24.8%
Diagnosis	42 (14)	£19,833,884	7.1%
Condition-specific research infrastructure	23	£12,335,623	4.4%
Care	17 (1)	£11,252,814	4.0%
Epidemiology	7 (4)	£2,935,725	1.0%
Phenomenology	27 (6)	£1,922,116	0.7%
Prevention	2	£151,770	0.1%

*Note: *numbers in parentheses indicate the number of grants for which the amount awarded was missing; +excluding grants for which the amount awarded was missing*

Looking solely at the grants in the four applied categories (Figure 2), over two-thirds (65.3%; n=115) focused on treatment and just over one-fifth (23.9%; n=42) on diagnosis, with only 9.7% (n=17) focusing on care and 1.1% (n=2) on prevention. It is possible however that many epidemiological studies examining associations are embedded within larger funding programmes that may fit under other categories. Full details of the information recorded can be found in the Technical Appendix.

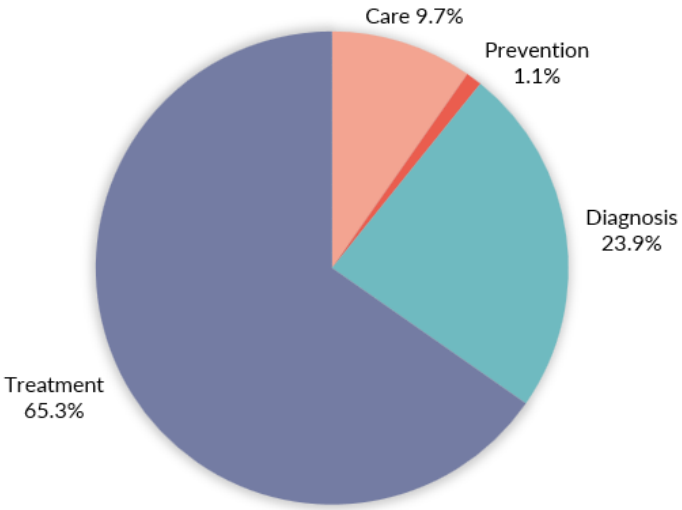


Figure 2. Relative proportions of grants addressing prevention, diagnosis, treatment and care

Consideration of the number of grants awarded does not account for possible systematic differences in size of award across categories or for possible differences in the type of funding, for example if some categories attract more fellowships or studentships than others. Therefore, we next calculated the amounts awarded across the full range of categories.

Details of the amount awarded were available for 463 grants. The 207 grants with missing information included all the MJFF grants (although details for one of these was found on the lead applicant's web page), and 95% of the remaining 100 were PhD studentships. As MJFF primarily funds research on disease mechanisms and 80% of the 108 included MJFF awards were in this category, the figures for the disease mechanism category are likely to be an underestimate.

For grants in the four applied categories, we further grouped the grants in each category according to whether the funding source was government or charity, or a combination of the two, and calculated the total amount invested by funding source (Table 3). All 17 missing government funding amounts were studentships, and all 13 missing charity funding amounts were awarded by MJFF.

There were 22 grants (12.5%) that included a focus on commercialisation; 17 of these were in the treatment category, with 2 each in diagnosis and care.

More than 1 in 10 of the grants (90.3%, n=159) focused on Parkinson's disease, 5.7% (n=10) on DLB, and the remaining 4% (n=7) on PSP, MSA, CBD, or unspecified Parkinsonism; see Figure 3. A small proportion of studies that focused on Parkinson's and were classified under that heading (7.4%, n=13) also included DLB or one of the rarer conditions as a secondary topic. There were 35 grants that covered Parkinson's alongside other conditions such as Alzheimer's disease or frontotemporal dementia.

Table 3. Number of grants in each of the four applied categories by funding source, and total funding allocated

Category	Government	Charity	Joint funding
Prevention	1	1	0
Diagnosis	20	22	0
Treatment	76	33	4
Care	12	5	0
Total	109	63	4
Total amount	£89,884,993 (17)	£10,387,840 (13)	£5,446,857

Note: numbers in parentheses are the number of grants with missing funding information

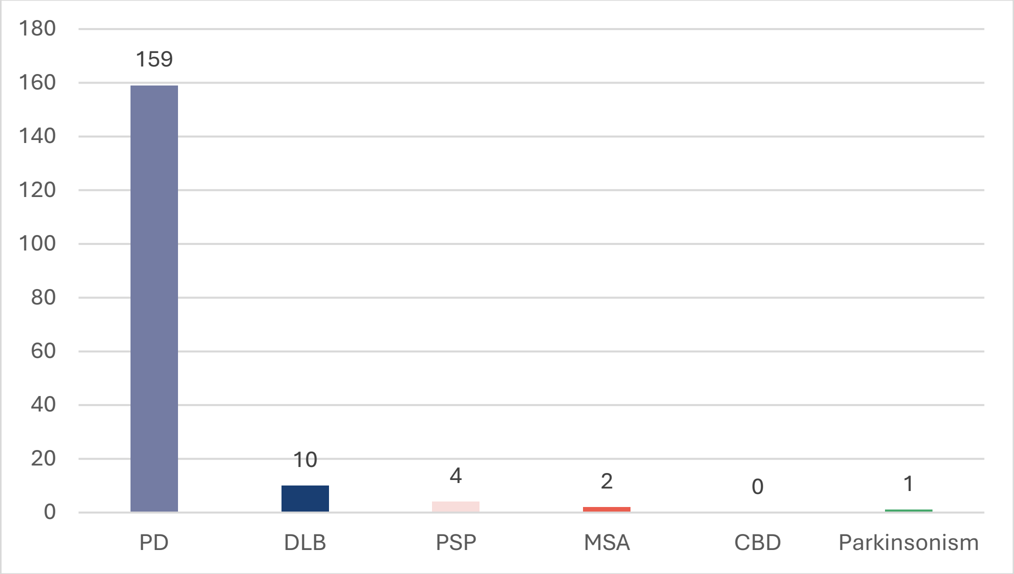


Figure 3. Total number of grants awarded for each condition

Only six grants explicitly set out to consider health inequalities. Inequalities were mentioned in the title or abstract of one prevention grant, two treatment grants, and three care grants. Three of these grants addressed more than one type of inequality: one prevention grant considered race and sex; one treatment grant considered age and sex; and one care grant considered age, sex, and race. One treatment grant focused solely on socio-economic status. Two care grants referred more generally to "social inequalities" and "socially, economically, and health-disadvantaged populations"; however, these descriptions lacked sufficient detail to identify specific inequalities. Other grants may have considered inequalities, but this was not evident from their titles or abstracts.

In terms of geographical distribution (Table 4), over half of the grants (52.3%) were awarded to 'golden triangle' institutions: London-based (34.7%) or Oxbridge (17.6%). The amount awarded to golden triangle institutions was £56,317,027, representing 53.3% of the total investment. Six grants were awarded to institutions outside the UK, including three to US institutions and one each to institutions in France, Italy, and Australia. These grants were all funded by UK-based charities, with four funded by Cure Parkinson's Trust and one each by Ataxia UK and Alzheimer's Research UK. The information is shown graphically on the UK map in Figure 4.

Table 4. Geographical distribution of grants by location of host institution

	Prevention	Diagnosis	Treatment	Care	Total
England					
London	1	10	43	7	61
Oxbridge	0	10	20	1	31
North East	0	9	10	2	21
South West	0	1	13	1	15
North West	1	3	6	2	12
West Midlands	0	1	6	0	7
South East	0	0	4	2	6
Yorkshire & Humber	0	2	3	0	5
East Midlands	0	0	0	0	0
Scotland	0	5	4	1	10
Wales	0	0	1	1	2
Non-UK locations					
USA	0	1	2	0	3
France	0	0	1	0	1
Italy	0	0	1	0	1
Australia	0	0	1	0	1

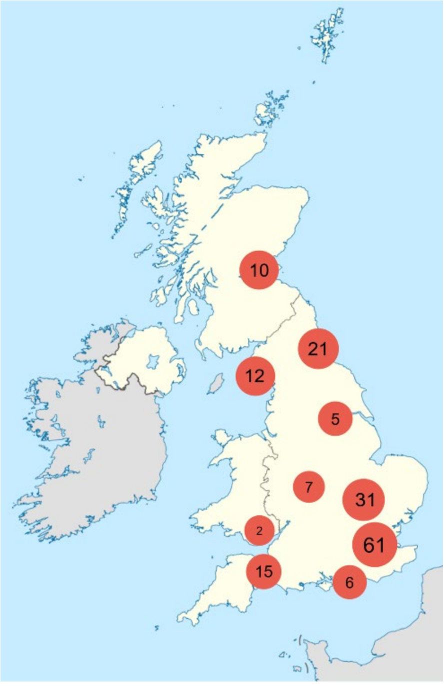


Figure 4. Geographical distribution of funds across the UK

Taking all four categories of applied research together, among the included grants, male researchers received a greater share of both awards and total funding than female researchers. Overall, 103 grants (58.5%) were awarded to male researchers and 73 (41.5%) to female researchers. This difference in grant numbers translated into a substantial disparity in funding amounts. Awards led by male investigators accounted for £71.9 million (71.4% of total funding), more than double the £28.8 million (28.6%) awarded to awards led by female investigators. This pattern was consistent across diagnosis, treatment, and care, where male researchers received proportionately higher funding relative to the number of grants awarded. There are some caveats to this, as the calculation assumes that applicant order in Dimensions.ai is accurate and that the first named applicant is the lead applicant of the grant.

Some applicant information was missing, primarily for EU funded grants. Where this was the case, we identified the information from the grant website and recorded solely information about the UK-based applicant. Where grants were awarded for device development and the device name was listed as the applicant, we identified and used the name of the product designer or Chief Executive Officer of the company involved.

Limitations in the information available meant that we could not fully capture all the expected details. This included type of award (e.g. programme grant, fellowship) and setting (e.g. community-based, hospital-based), and summary statistics for funding amounts other than the mean (median, mode, range and interquartile range).

Consultation on research funding allocation

Our stakeholder consultation on funding allocation was described in our first interim report[7]. In summary, consultees felt that all four applied research categories were important and wished to see more research especially in the prevention and care categories. They noted that despite the emphasis on the treatment category, progress had been limited, with the gold standard treatment unchanged since the 1960s. They were concerned about the geographical distribution of funding, limited attention to addressing health inequalities, and underfunding of research on the rarer conditions, and wondered how the whole research sector could work together more effectively.

3 The research evidence landscape

What we did

We searched for research literature and systematic reviews written in English that were indexed in the PubMed database. The search covered studies published between 1st January 2019 and 28th October 2024 that mentioned Parkinson's, DLB, PSP, MSA, or CBD. Each title and abstract was initially screened by a single reviewer. The search yielded 60,705 records, which were initially screened by a single reviewer. Of these, 30,100 were excluded and the remaining 30,605 were allocated to one of the seven categories based on information in the title and abstract, apart from 14 that described aspects of research infrastructure which were not considered further. A second reviewer then screened the records deemed relevant to the four applied research categories to check they were correctly allocated. The flowchart summarising the process is shown in Figure 5. The full methodological protocol is available in the Technical Appendix.

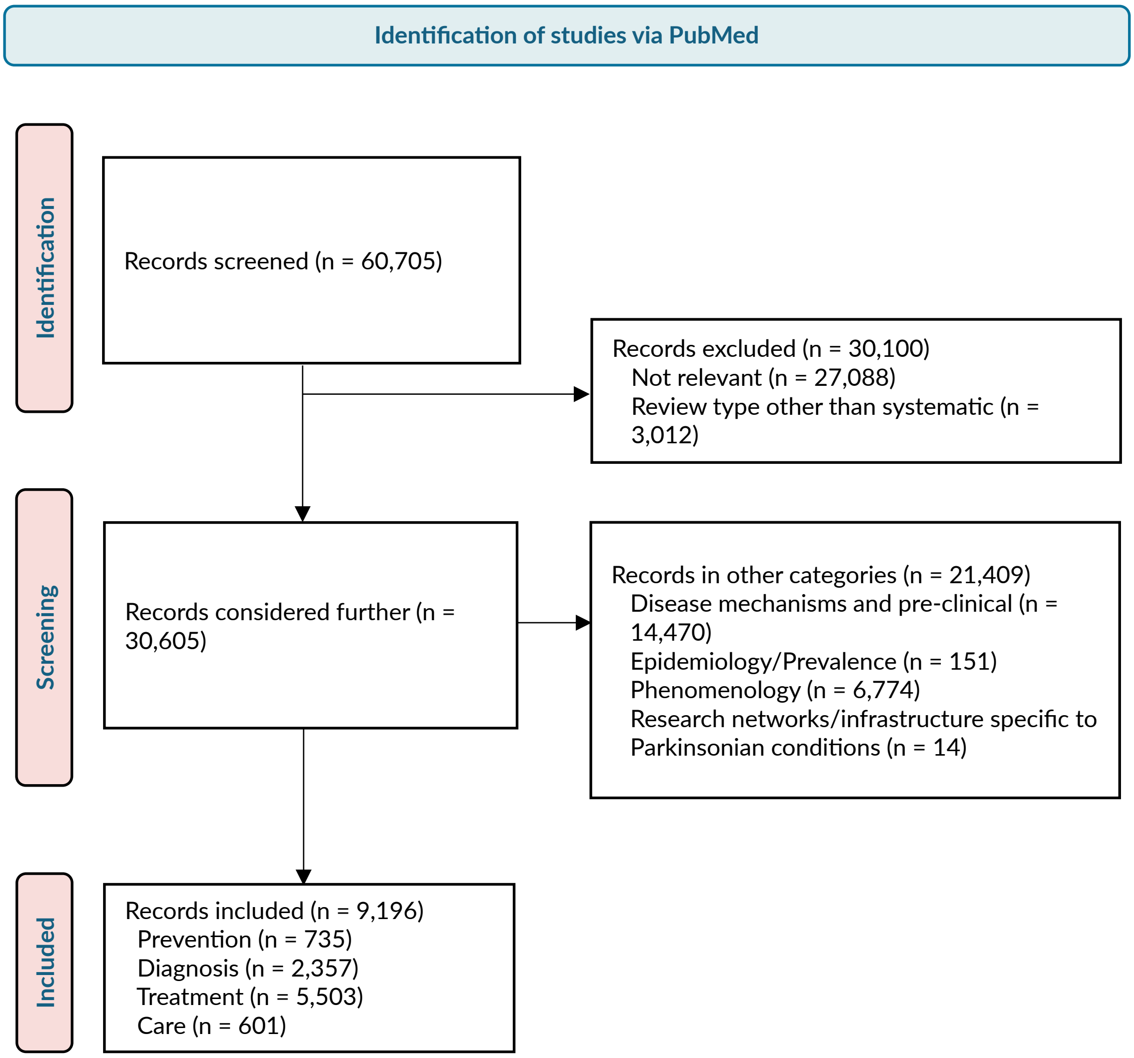


Figure 5. Flowchart: research evidence

What we found

Overall, 30.0% (9,196 articles) were classified into one of the four categories of applied research (Figure 6), with the remaining 70.0% (21,409 articles) representing papers that were focused on the remaining categories (Figure 5).

Looking just at primary research, the annual number of publications showed an increasing trend over time, rising from 1,060 papers in 2019 to 1,302 in 2024, with a post-COVID peak (1,453 papers) in 2022. Over the five-year period, the UK ranked fifth globally in volume of outputs, with 464 papers.

Full details of all the information we recorded can be found in the Technical Appendix.

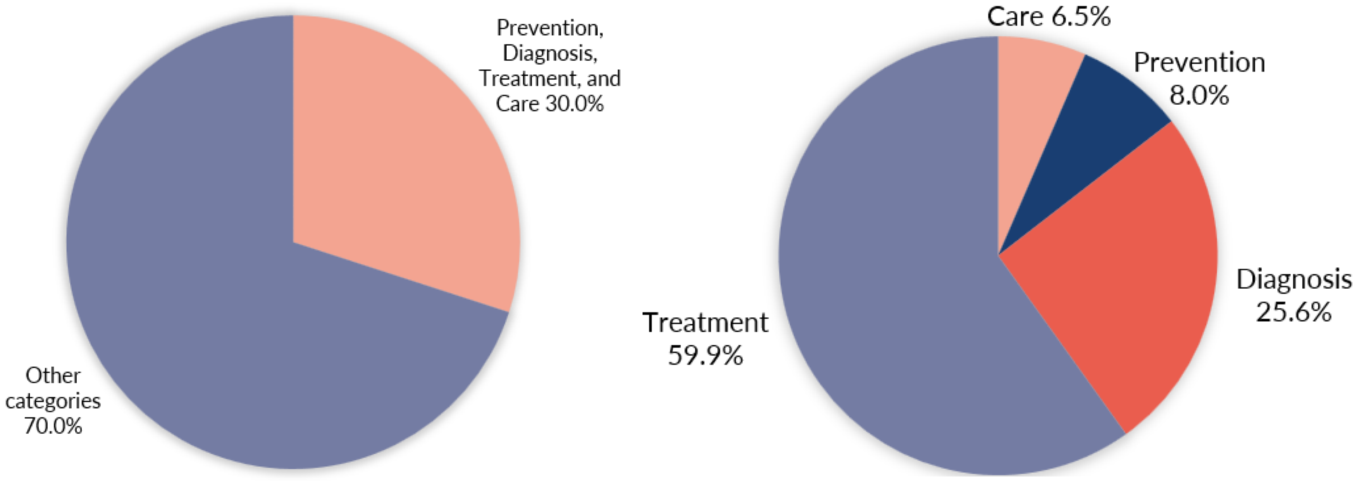


Figure 6. Distribution of research evidence across categories: including all categories (left) and restricted to the four applied research categories only (right)

The number and proportion of primary studies and systematic reviews in each of the four applied research categories are summarised in Table 5.

Table 5. Number and proportion of primary studies and systematic reviews in each applied research category

Category	Primary literature	Systematic reviews
Prevention	541 (6.9%)	194 (14.0%)
Diagnosis	2,159 (27.6%)	198 (14.4%)
Treatment	4,577 (58.6%)	926 (67.2%)
Care	540 (6.9%)	61 (4.4%)
Total	7,817 (100%)	1,379 (100%)

Primary research studies accounted for 7,817 of the included articles. Over half (58.6%; n=4,577) focused on treatment and just over a quarter (27.6%; n=2,159) on diagnosis, with 6.9% (n=540) focusing on care and 6.9% (n=541) addressing prevention. The majority (6,996) focused on Parkinson's with small proportions focusing on DLB, PSP, MSA, CBD or unspecified Parkinsonism (Figure 7).

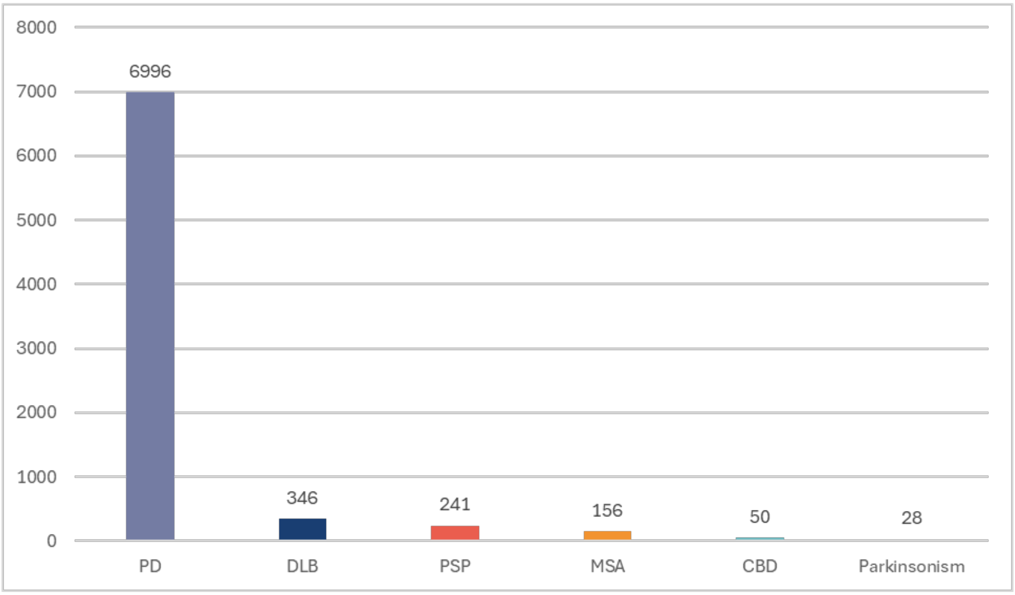


Figure 7. Primary research studies by diagnosis

Systematic reviews accounted for 1,379 of the included articles. Three quarters (67.2%; n=926) focused on treatment, 14.4% (n=198) on diagnosis, 14.0% (n=194) on prevention and 4.4% (n=61) on care.

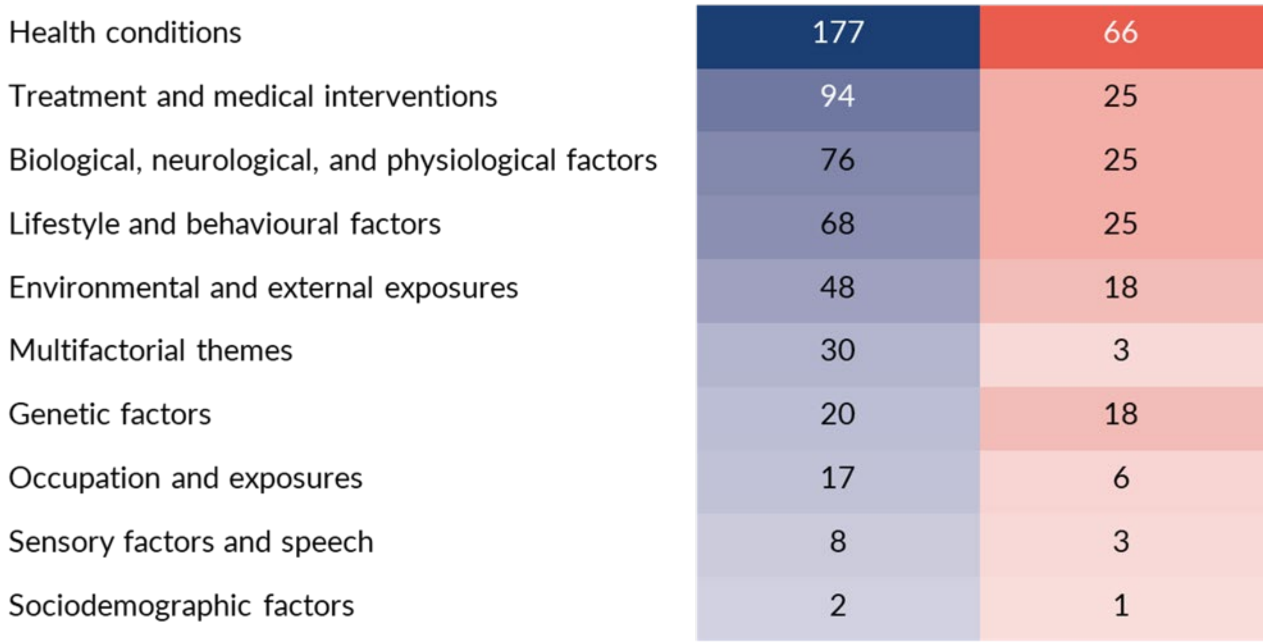
Health inequalities were mentioned in the title or abstract of only 5.9% (n=462) of primary research studies. Of these, 139 studies referred to more than one inequality, most commonly age and sex (n=106). The most frequently mentioned sources of inequality were sex (269 studies) and age (242 studies). Race was mentioned in 55 studies, while other inequalities were far less frequently reported, including geographical location (17 studies, e.g., comparing people living in the North and South of England), socio-economic status (15 studies), disability (10 studies), and urban/rural status (8 studies). Religion or belief (3 studies), gender (2 studies), and caring responsibilities (1 study) were rarely mentioned.

Health inequalities were mentioned in the title or abstract of only 3.7% (n=51) reviews. Care was the only category where inequalities were not mentioned at all. 16 reviews mentioned more than one inequality, most commonly age and sex (n=9). The most frequently mentioned sources of inequality were age (26 reviews) and sex (24 reviews), which appeared together in 9 of the reviews. These were followed by race (13 reviews) and socio-economic status (7 reviews). Disability (2 reviews) and geographic inequalities (2 reviews) were rarely mentioned, while caring responsibilities, gender, religion or belief, and urban/rural status were not mentioned in any review.

Next, we reviewed the titles and abstracts of all articles in each category to provide a more fine-grained picture of the topics covered.

Applied research on prevention

The primary prevention research literature has mainly examined associations between a wide range of factors and the risk of developing Parkinson’s (Figure 8). The greatest emphasis was on presence of other health conditions, such as diabetes, cardiovascular disease or digestive disorders. Of the 177 papers categorised under health conditions, only 40 (22.6%) focused on mental and behavioural disorders. Within this subset, most studies explored sleep-wake disorders (n=17), mood and emotional disorders (n=7), or trauma and stress (n=6). The second most common category, medical treatment for other conditions, refers to studies investigating whether drugs or procedures prescribed for unrelated health issues influence the risk of developing Parkinson’s. These were followed by studies on intrinsic (biological, neurological or physiological) factors, lifestyle or behavioural factors such as diet, physical activity or smoking, and environmental exposures. Occupational exposure was considered in only 17 primary studies, most focusing on exposure to toxins such as pesticides.



Health conditions	177	66
Treatment and medical interventions	94	25
Biological, neurological, and physiological factors	76	25
Lifestyle and behavioural factors	68	25
Environmental and external exposures	48	18
Multifactorial themes	30	3
Genetic factors	20	18
Occupation and exposures	17	6
Sensory factors and speech	8	3
Sociodemographic factors	2	1

Figure 8. Topics covered in the prevention category

Across the 735 papers identified, 541 were empirical studies and 194 systematic reviews, over one quarter of the total. This represents the highest proportion of systematic reviews of the four applied research categories. Within the empirical studies, 99.8% were observational; only one primary study focused on prevention approaches, specifically, an insecticide ban aimed at preventing Parkinson's in Central California. This highlights a critical gap: despite the breadth of association research, there is almost no evidence on interventions designed to reduce Parkinson's risk.

Despite directly receiving a meagre 1.1% of UK Parkinson's research funding, prevention and epidemiological research demonstrates strong outputs relative to the proportion of funding allocated, contributing 5% of primary literature and 9% of systematic reviews. This disparity reveals an exceptional return on investment: while epidemiological studies often require significant upfront capital to establish cohorts and infrastructure, they offer a 'long tail' of productivity where data can be re-analysed cost-effectively for years. The current output suggests that this field is highly efficient, but resource constrained. If a fractional investment can generate such a disproportionate share of the evidence base, scaling up funding would not only sustain this momentum but allow for the more resource-intensive prevention intervention studies that are currently missing.

A strategic pivot from observational research toward prevention-focused intervention studies is now essential. Where association research remains necessary, the field must diversify by prioritising under-explored, modifiable risk factors, such as occupational and environmental determinants, where preventative efforts offer the greatest potential for impact. Evidence could be further strengthened by integrating electronic health records with cohort data; this would enable the large-scale longitudinal analyses often precluded by the limited sample sizes in current Parkinson's research. Ultimately, future work must move beyond simple associations to develop multifactorial risk models combining genetics, lifestyle, and environment, alongside mechanistic studies that clarify causality and establish the optimal timing for preventative action.

Applied research on diagnosis

Across primary literature, research on diagnosis focused primarily on assessment and accuracy (n=1,251, 57.9%) and differential diagnosis (n=705, 32.7%), with prodromal diagnosis, (i.e., those studies seeking to identify Parkinson's and related diseases prior to the appearance of motor symptoms), accounting for 8.8% (n=190) of studies. Limited attention was devoted to communication of the diagnosis (n=1, 0.05%) or the experience of receiving a diagnosis (n=12, 0.5%). Of the 198 included reviews, one investigated communication of the diagnosis (0.5%), 129 investigated assessment and accuracy (65.2%), 42 investigated differential diagnosis (21.2%), and 26 investigated prodromal diagnosis (13.1%).

Across the diagnostic literature, a range of health technology approaches is used to identify, classify, and monitor Parkinson's and related conditions. These span risk, prediction and early detection approaches that seek to identify at-risk or prodromal individuals before motor symptoms emerge; clinical and symptom-based assessments, which rely on structured evaluation of motor and non-motor features using established scales and criteria; and physiological and biomarker-based approaches, including biochemical, genetic, and neurophysiological measures. Imaging and instrument-based approaches use technologies such as MRI, PET, SPECT, or EEG to visualise or quantify neurological change, while sensory and perceptual domain approaches assess functions such as olfaction, vision, hearing, or gait as early or differential indicators. Therapeutic or intervention-linked diagnostics are designed to guide treatment selection, stratify patients, or monitor response, and data-driven and computational approaches apply algorithmic or AI-based analyses to multimodal data for classification and prediction. Underpinning these are methodological and tool development activities, which focus on designing, validating, and harmonising diagnostic tools, protocols, and consensus standards. These health technology approaches are summarised in Figure 9.

Overall, research on diagnosis across the primary literature is dominated by studies focused on diagnostic assessment and accuracy and differential diagnosis, together accounting for most of the evidence base, while prodromal diagnosis represents a much smaller but growing area. Very limited attention is paid to communication of the diagnosis or the lived experience of receiving a diagnosis. Methodologically, diagnostic research employs a wide range of health technology approaches, including clinical and symptom-based assessments, physiological and biomarker-based measures, imaging and instrument-based techniques, sensory and perceptual assessments, and increasingly data-driven and computational methods. Imaging, biomarker, and algorithmic approaches feature most prominently, reflecting a strong orientation towards quantifiable and technology-enabled diagnostics. Collectively, this body of work illustrates a diagnostically mature and technically advanced research landscape, with emphasis placed on measurement, classification, and precision rather than on care delivery or patient-facing aspects of diagnosis.

The diagnostic evidence base for Parkinson's and related syndromes benefits from substantial funding and high levels of technological innovation, particularly in imaging, biomarker discovery, and AI-supported approaches. Diagnostic research activity and funding are also concentrated within a small number of centres, underscoring the need to widen access to funding and promote a more equitable geographic distribution of diagnostic research capacity. Across the literature, there is an over-reliance on observational and retrospective studies, with insufficient emphasis on intervention-linked diagnostics, prospective validation, and progression through the translational pipeline. Greater focus is needed on real-world implementation and integration of diagnostics into health and care systems, so that advances in accuracy lead to tangible improvements in clinical decision-making and patient experience. Addressing health inequalities must become a core priority, moving beyond age and sex to consider intersecting social, ethnic, and geographic factors that shape diagnostic access and outcomes.

Future diagnostic research should align more closely with prevention agendas, applied research, and health system transformation, ensuring that the innovation demonstrated can deliver equitable, person-centred, and clinically meaningful improvements in diagnosis.

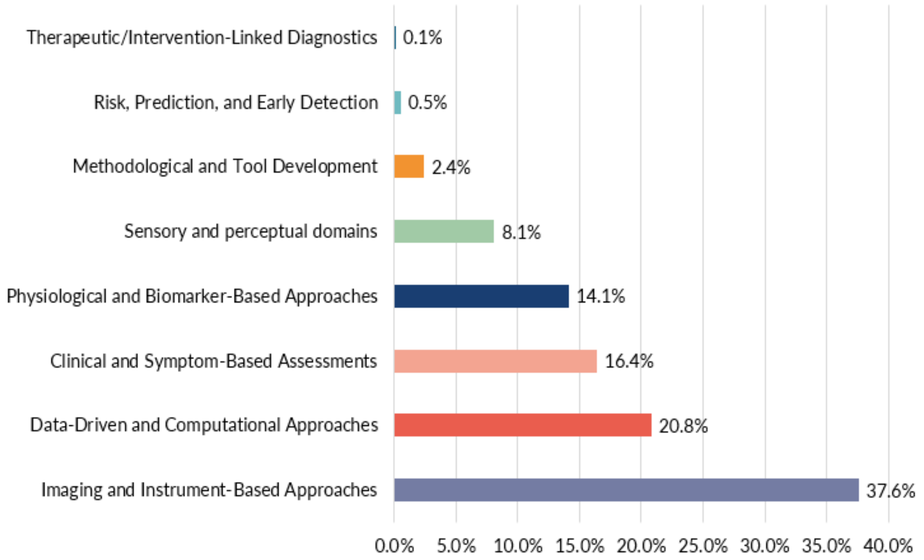


Figure 9. Methods and approaches in diagnosis research

Applied research on treatment

Primary research in the treatment domain is predominantly focused in two areas:

- the development and evaluation of therapies (n=1,838), such as establishing safety and efficacy, optimising treatment regimes, and monitoring side effects; and
- motor symptoms (n=1,390), including general motor function and gait, as well as tremor, freezing of gait, balance, and posture.

Other commonly experienced symptoms such as anxiety, depression, cognitive impairment, fatigue, pain and communication difficulties receive less attention (n=746). These together account for about half of the number of primary research studies seen for motor symptoms. A small number of studies (n=270) investigated autonomic and regulatory problems, such as sleep disturbance, swallowing, bladder dysfunction, cardiovascular instability, respiratory changes or sensory changes. An even smaller proportion focused on psychosocial and lifestyle issues (n=109) such as quality of life or physical activity. There is some work on biomarkers and biological processes (n=224), primarily using brain imaging techniques. See Figure 10 for a breakdown.

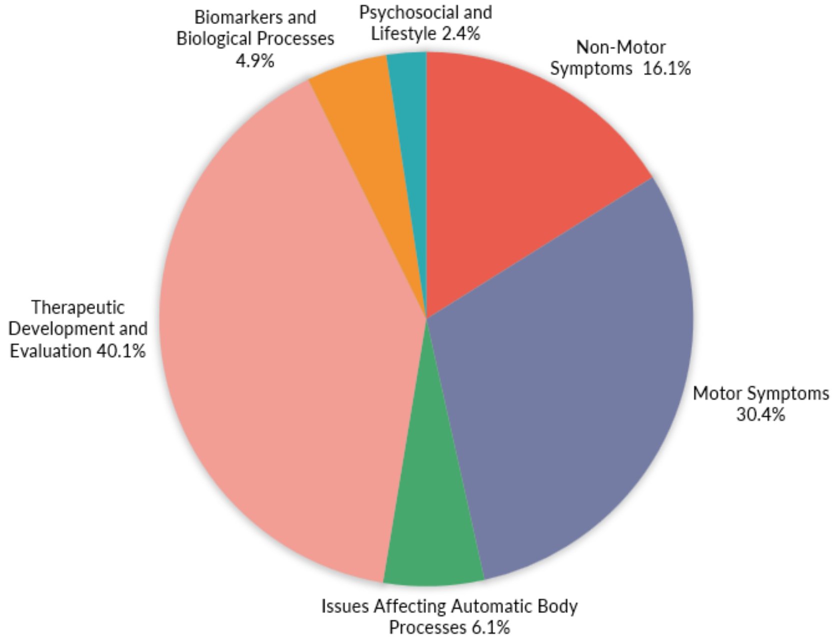


Figure 10. Targets of treatment research

Of the 926 reviews, 32.5% (n=301) focused on the development and evaluation of therapies, 36.1% (n=334) on motor symptoms, 22.0% (n=204) on other common symptoms, 5.0% (n=46) on autonomic and regulatory problems, 2.6% (n=24) psychosocial and lifestyle issues, and 1.8% (n=17) on biomarkers and biological processes. Reviews are proportionally more likely to focus on motor and non-motor symptoms compared to primary studies and are less likely to focus on the development and evaluation of therapies and biomarkers and biological processes.

The approaches used to address treatment in primary research are summarised in Figure 11. Intervention research is dominated by studies of drug treatments and deep brain stimulation (DBS; n=2,679), including extensive focus on optimising existing medications and refining DBS applications, with less emphasis on developing new disease-modifying therapies. Neurological and brain-based approaches (n=531) focus on non-invasive interventions, including transcranial magnetic stimulation and transcranial direct current stimulation, sensory cueing to support gait and motor control, and regenerative and technology-assisted strategies. Digital and remote technology studies (n=441) focus on the use of wearables, remote patient monitoring and virtual reality applications, primarily to assess or manage motor symptoms or gait. Together these three sub-categories comprise nearly 80% of all treatment studies (n=3,651, 79.7%). The remaining sub-categories include exercise and movement-based therapies (n=456), including general individual and group-based interventions, aerobic, resistance, treadmill and balance training, and dance interventions, rehabilitation and allied health interventions (n=242), psychological support and self-management (n=62), diet, gut and microbiome approaches (n=62) and complementary and creative therapies (n=104) such as acupuncture and music therapy.

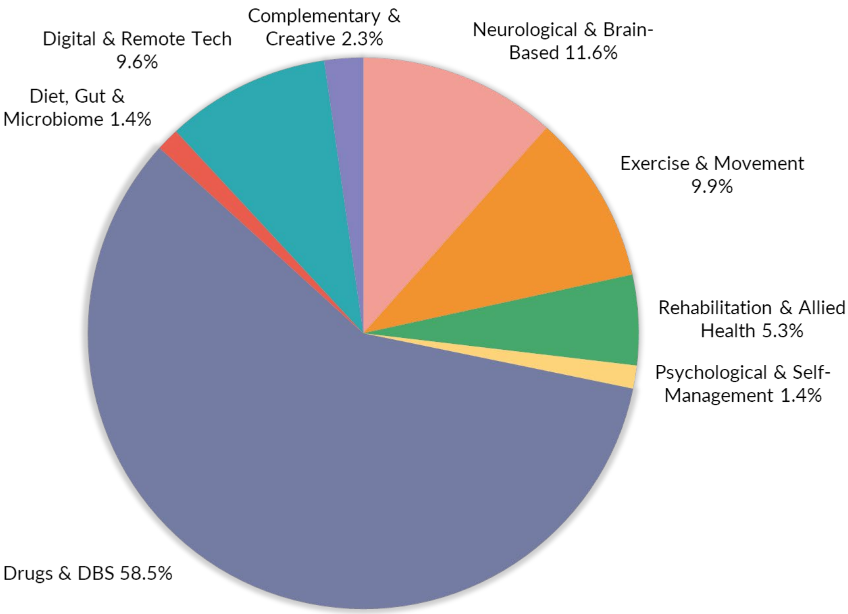


Figure 11. Methods and approaches used in treatment research

Of the 926 reviews, 40.3% (n=373) focused on drug treatments and DBS, 13.3% (n=123) on neurological and brain-based approaches, 8.4% (n=78) on digital and remote technology studies, 19.3% (n=179) on exercise and movement-based therapies, 8.7% (n=80) on rehabilitation and allied health interventions, 2.2% (n=20) on psychological support and self-management, 3.0% (n=28) on diet, gut & microbiome approaches, and 5.0% (n=46) on complementary and creative therapies. Reviews are therefore proportionally less likely to focus on drugs and DBS and neurological and brain-based interventions compared to primary studies.

Primary research in the treatment domain includes a wide range of study types. Over half the studies were observational or epidemiological (53.6%, n=2,456). This includes routine data or case-note reviews (n=689), case–control (n=595) or case series (n=593) studies, prospective cohorts (n=226), and other longitudinal studies (n=97), as well as surveys (n=105), secondary analyses (n=113), and retrospective cohorts (n=37).

Intervention studies comprise just under 40% of studies (38.8%, n=1,775) and are roughly equally divided between randomised controlled trials (RCTs; n=871) and experimental methods (n=904). There were 133 Phase 1, 633 Phase 2, 100 Phase 3, and 5 Phase 4 RCTs. Among the experimental studies there were 679 pre/post comparison studies, 124 non-randomised trials, 27 open-label trials, and 74 studies focusing on device development.

The remaining study design types were modelling (4.5%, n=206), qualitative and mixed methods (2.1%, n=96), and consensus (e.g., Delphi) methods (1%, n=44).

Of the 4,577 papers included in the treatment category, 97% (n=4,455) focused on people with Parkinson's as the main condition, 1% (n=49) on people with DLB, the remaining 2% comprised 39 studies investigating PSP, 32 studies investigating MSA, and only 2 studies investigating CBD. Proportions were similar for reviews.

Most studies (94.9%, n=4,344) focused exclusively on Parkinson's and related conditions with only 5.1% (n=233) including people with non-Parkinsonian conditions such as Alzheimer's and multiple sclerosis.

Reviews were more likely than primary studies to include people with non-Parkinsonian conditions (12.6%, n=117).

The current treatment research landscape in Parkinson's is heavily weighted towards pharmacological therapies, DBS, and the management of motor symptoms. This is also reflected in the distribution of RCTs, where pharmacological and stimulation-based interventions account for the majority of later-phase (Phase 3 and Phase 4) studies. Other commonly experienced symptoms, such as cognitive impairment, communication difficulties, anxiety, depression, pain and fatigue, receive much less research attention than motor symptoms. This imbalance is evident in the RCT evidence base, where interventions targeting psychological, cognitive, psychosocial, and self-management outcomes are relatively few and are overwhelmingly confined to Phase 1 and Phase 2 trials. Autonomic and regulatory problems, and psychosocial and lifestyle factors, are particularly under-studied. Psychological support and self-management approaches, while representing only a small proportion of primary studies, appear more prominently in reviews, suggesting high interest but limited resource. Targeted funding is needed to support progression to later-phase trials and eventual implementation.

Although drug treatments and DBS dominate intervention research, much of the effort focuses on optimising existing therapies rather than developing new disease-modifying treatments. This pattern is reflected in the RCT evidence base, with many Phase 1 and Phase 2 pharmacological trials reported but relatively limited progression towards trials explicitly designed to assess disease modification. Exercise and movement-based therapies, task-specific movement interventions, rehabilitation and allied health approaches, and complementary and creative therapies are represented in early-phase RCTs but rarely progress to Phase 3 trials. Digital and remote technologies are increasingly evaluated in RCTs but remain concentrated in Phase 1 and Phase 2 studies and are primarily focused on motor outcomes.

Treatment research overwhelmingly focuses on Parkinson's, with minimal attention to DLB, PSP, MSA, and CBD. Increased and targeted funding for these conditions would help to address significant unmet clinical need.

Applied research on care

Primary research in the care category was primarily descriptive (79.8%, n=431) with interventions accounting for only 20.2% (n=109) of studies. Hardly any of these intervention studies were RCTs; we found only four Phase 2 and two Phase 3 trials.

Table 6 summarises the sub-categorisation of primary studies in the care category. The aspects of care most frequently targeted by primary research studies were health care provision and health care systems, including costs of care, accounting for more than a third of primary research (35.9%, n=194). Studies of community and family support, including informal caring, accounted for over a quarter of primary research (23.3%, n=126), although only a very small number involved interventions. Less emphasis was given to patient experience and well-being (14.6%, n=79) or to management of symptoms affecting daily living (5.7%, n=31). This latter category covered studies of how care could, for example, improve dental and mouth care or improve balance and reduce falls. COVID-related studies comprised 8.3% (n=45) of the total and end-of-life and palliative care was addressed in 12.0% (n=65).

Table 6. Focus of primary studies in the care category

Category	Descriptive studies	Intervention studies
Healthcare provision & systems	142	52
Community & family support (including carer issues)	111	15
Experiences and well-being	67	12
End-of-life (incl. palliative care)	56	9
COVID-related	37	8
Management of symptoms that affect daily living	18	13
Total	**431**	**109**

The types of interventions studied in the care category and their relative proportions of the total number of intervention studies are summarised in Figure 12. The greatest emphasis was on technology-based support (n=40). Clinical or medical interventions were also commonly studied (n=27), alongside psychological and psychosocial interventions (n=17) and education, training, and tools (n=15). Therapies and rehabilitation received the least attention, with only 10 studies.

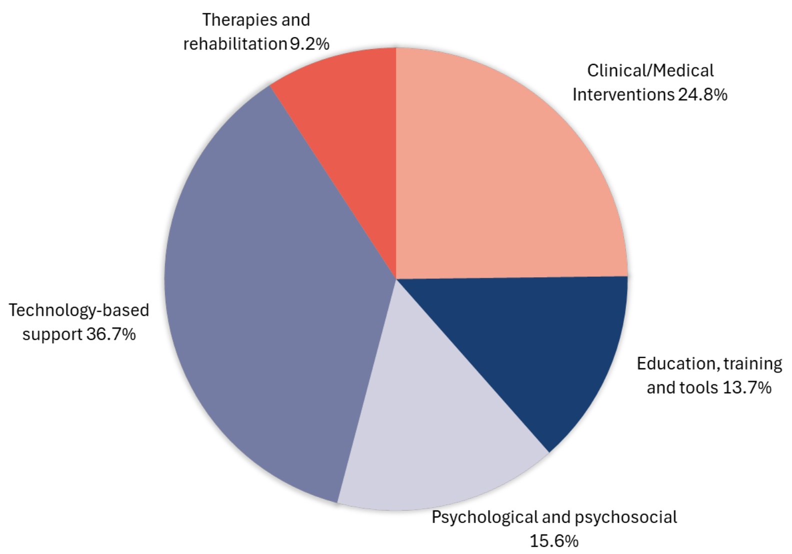


Figure 12. Focus of intervention research in the care category

There is considerable research that describes lived experiences of having Parkinson's or related conditions as well as unpaid carers' experiences. There is also a good amount of research describing care and care systems both in the community and in hospitals. However, the number of care intervention studies is low. In addition, there is a paucity of research focusing on palliative and end-of-life care (PEoLC). Of the 540 articles explored, only 65 (12%) concentrated on this area. Most of them focused on the broad topics of palliative care or end of life. Far fewer examined interventions or care approaches, e.g., advance care planning (5/65), assisted dying (3/65) or place of death (4/65). The studies highlighted gaps in timely communication, continuity and coordination of care, prognostication, and support for carers. The necessity for these areas to be addressed was consistently emphasised by experts-by-experience (carers, clinicians, nurses and third-sector staff) during the online consultations.

Further research to develop and evaluate interventions to improve care, including PEoLC, is urgently needed. Priority areas could include research focused on therapies provided by allied health professionals that aim to help people sustain or re-gain aspects of function, including rehabilitative, physical, psychological and educational interventions. Research is also needed to identify effective approaches to supporting unpaid carers, both in their caring role and in maintaining their own health and well-being across the care trajectory.

Research evidence in relation to stakeholder priorities

In the second interim report on this project[3], we explored the information available from surveys and the Parkinson's ON app about the research priorities of people living with Parkinson's and the practitioners who support them. We supplemented this with further consultations. We briefly summarise the key points here.

Priorities ranged widely across motor and non-motor symptoms and other issues, all of which were seen as deserving attention from researchers. Key priorities relating to motor symptoms were balance, falls, tremor and motor dexterity, and for non-motor symptoms key priorities were sleep, urinary problems, fatigue and psychological health. Other priorities were medications and medication regimes, including tailoring to sub-type and stage, and exercise for strength and balance. Some symptoms that are intimate and can be invisible such as the impact on sexual functioning may not emerge as priorities unless specifically and sensitively explored and so may be missed in surveys or priority-setting exercises.

Practitioners commented on the lack of evidence on which to base decisions about how best to plan and deliver services that can support people with these conditions and their unpaid carers compassionately across the pathway from diagnosis to end of life, for example receiving and adjusting to the diagnosis, managing the impact of symptoms on everyday activities, addressing commonly experienced symptoms other than those related to motor function, maintaining well-being, and reaching out to those who may be reluctant to seek help.

Perspectives of people living with the condition, unpaid carers and practitioners on research priorities do not necessarily align, so all should be considered.

4 Discussion

This project has its origins in concerns that people living with Parkinson's and related conditions are not receiving the kinds of services and support that these complex conditions warrant, an issue that is increasingly salient as our ageing population leads to growing numbers affected. Applied research has an important role to play in providing evidence to guide development and improvement of effective health and social care services and wider provision for example through the voluntary sector. While this mapping exercise has demonstrated a robust funding scenario for UK Parkinson's research overall and, internationally, an extensive body of research evidence, applied research is relatively under-represented, with significant gaps.

The UK research funding landscape benefits from a strong charity sector alongside NIHR and research council commitment and a climate of innovation. There is an understandable strong focus on disease mechanism and pre-clinical studies. However, only around one-quarter of funding is allocated to applied research. Among applied research grants, prevention and care are relatively under-represented, with most funding going to treatment studies. Geographical distribution is inequitable with over half of grants allocated to researchers concentrated in the 'golden triangle', and male researchers receive over 70% of the available funding.

The international research landscape covers the broad spectrum from foundational basic science to applied research, and just under one-third of the research evidence identified for this review could be classified as applied research. Comparison across categories suggests clear gaps in relation to prevention and care, a focus on motor symptoms with relatively less attention to other commonly experienced symptoms such as anxiety, depression, cognitive impairment, fatigue, pain and communication difficulties within the treatment domain, limited focus on non-medical lifestyle and psychosocial approaches, and limited consideration of patient experience, especially in the diagnosis category.

Further, there is very little emphasis on addressing health inequalities, either singly or through an intersectional approach. Differences due to age and sex are sometimes considered, although may require more emphasis, but other sources of diversity are rarely addressed. Limited evidence about rarer Parkinsonian conditions is likely to negatively affect the experience of people with these conditions and their unpaid carers.

Across all categories, but especially prevention and care, there is a need to move the emphasis from observational research to intervention. Applied research needs an increased focus on real-world implementation and integration of new systems, practices and treatments into health and care services, directly improving patient and carer experience.

We recommend therefore that funders seek to identify innovative approaches that can facilitate a radical change of emphasis in applied research on Parkinson's disease and related conditions. The first step is to place the person with Parkinson's (or a related condition) at the heart of this endeavour and ensure that applied research addresses the priorities of people affected and their unpaid carers, serves the overall goal of enabling people to live as well as possible with the condition, and provides a foundation for services to offer compassionate and effective support across the pathway from pre-diagnosis to end of life. Involving people with lived experience in identifying priorities and in making funding decisions will help to ensure relevance. Broadening the focus to include, for example, greater emphasis on primary prevention, addressing inequalities or non-medical rehabilitative, psychological and lifestyle interventions may mean bringing in researchers from a wider range of disciplines who may not (yet) have engaged in Parkinson's research and a wider range of research-aware clinicians with experience of delivering services and supporting development of collaborations. Research training models may also need adjusting to facilitate greater emphasis on real-world implementation. Progress could be facilitated by a co-ordinated approach among funders and judicious use of targeted funding calls.

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Data availability and access

This report is based on two large datasets: a dataset of research funding awards and a bibliographic dataset of published research.

The research funding analysis is based on data extracted from Dimensions.ai and comprises approximately 1,000 grant records, of which around 650 were included in detailed analyses. These data are held across several working Excel files developed for internal analytical purposes. Due to the structure and format of these files, they are not currently suitable for public release in full. A cleaned dataset relating to the subset of 176 grants examined in greatest detail can be made available on reasonable request.

The literature mapping component draws on systematic searches in PubMed that identified 60,705 reports, of which 30,100 were excluded during screening as not relevant to the scope of the review. The remaining reports informed the analyses presented in this report. Owing to the size of the bibliographic dataset and the format of the underlying reference management files, the full dataset is not published alongside this report. To support transparency and reproducibility, full details of the search strategies, inclusion criteria, and screening processes are reported. Information on included reports and summary-level extracted data can be made available on reasonable request.

Access to any shared data will be subject to appropriate use for research or policy purposes.

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