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Dementia and neurodegeneration
University of Exeter

NIHR Policy Research Unit in Dementia and Neurodegeneration: DeNPRU Exeter

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Parkinson's disease: Mapping the research evidence and funding landscape

Aims of the project:

1. To understand the nature of the research evidence on prevention, diagnosis, treatment and care for people with Parkinson's and related conditions.

2. To understand where and how research funding is being used.

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Mapping published research studies

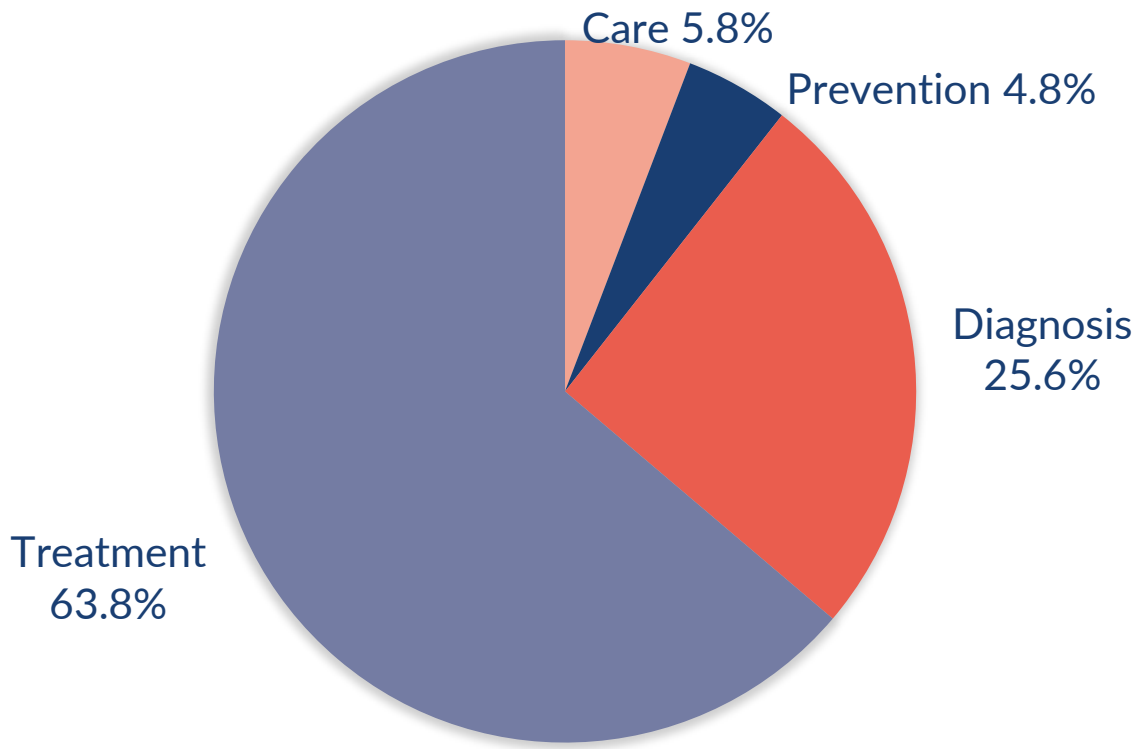
Conditions covered

- Parkinson’s disease (PD)
- Multiple system atrophy (MSA)
- Progressive supranuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- Parkinson’s disease dementia (PDD)
- Lewy Body dementia (LBD)

We searched for all Parkinson's-related research published in English in the last 5 years.

We categorised 31,123 research records according to our four themes.

We categorised applied research across the 4 themes

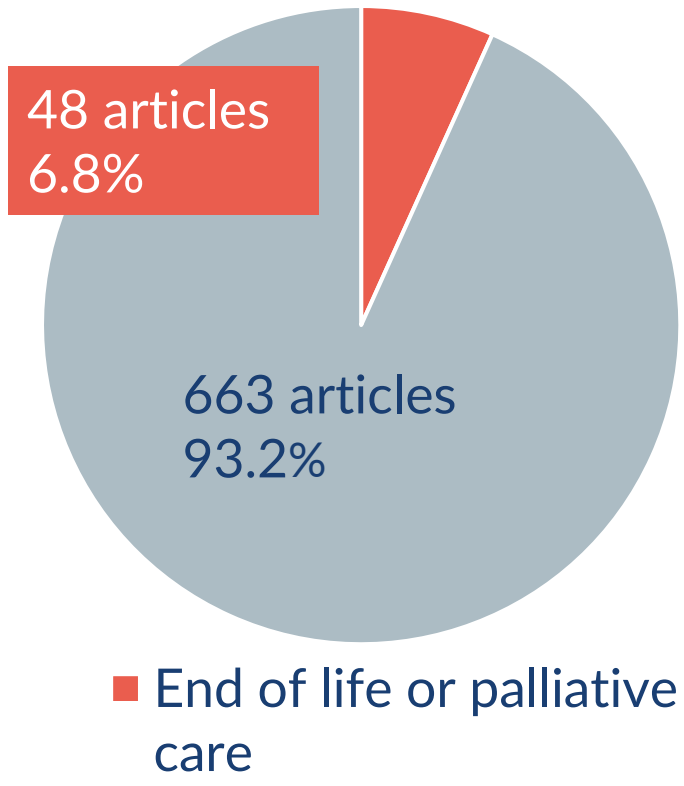


Category	Primary literature
Prevention	585 (4.8%)
Diagnosis	3,143 (25.6%)
Treatment	7,817 (63.8%)
Care	711 (5.8%)
Total	*12,256*

Relative proportions of published articles reporting primary research that addressed prevention, diagnosis, treatment and care

Within care research we noted studies on end of life and palliative care

Number of studies



Conditions studied

Parkinson's disease (39)

Parkinson's disease and parkinsonism (2)

Dementia with Lewy Bodies (6)

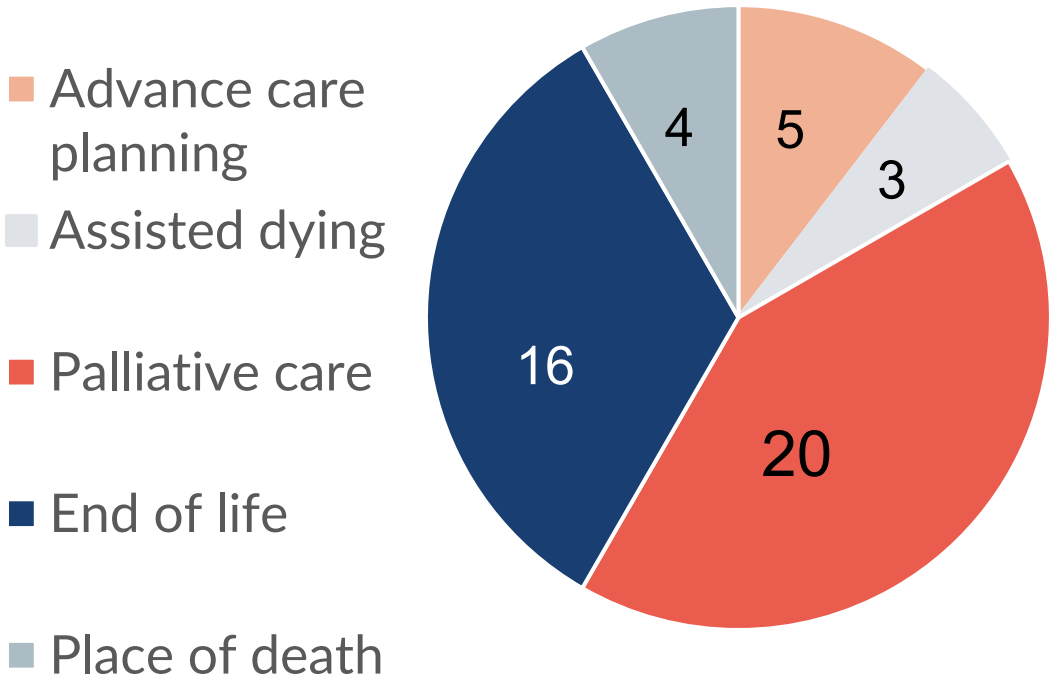
Multiple Parkinsonian conditions (1)

9 also included other conditions

13 different countries

USA 19 UK 10

Themes of research on end of life and palliative care



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Consultation

Palliative and end-of-life care consultations

We held two online consultations:

- One with a clinical academic who had cared for one parent with Parkinson's disease and one parent with Lewy body dementia.

- One with six varied professionals including old age physicians, a specialist Parkinson's disease nurse, and third sector staff including an end-of-life doula.

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What does good palliative and end-of-life care look like for someone with Parkinson's conditions?

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Expert by experience	Professionals
• The need for awareness and understanding of the diagnosis and care pathway with specific focus on future care planning • Timeliness of discussions related to prognosis and palliative care • Feeling prepared and having time to digest information	• Better information provision • Support for carers to understand symptoms and prognosis

It should be clear what the prognosis might be, what the support might need forwards.

It should be made obvious what the process is.

Needs enhanced staff and patient awareness.

What challenges (or gaps) have you seen in relation to palliative and end-of-life care?

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Expert by experience	Professionals
• Lack of provision of basic information • Lack of continuity of care • Disjointed physical and mental health services	• Increasing demand but lack of funding • Gaps in the pathway between institutions and across conditions • Prognostication isn't precise

Mum had regular appointments with her neurologist, and he had some knowledge of Parkinson's, but it was a bit hit and miss.

When is end of life with rarer conditions? There are no early conversations about this.

Lack of understanding about palliative teams can do.

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What do you think should be prioritised for Parkinson's related research in palliative and end-of-life care?

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Expert by experience	Professionals
• Understanding signs and symptoms – information being provided in a timely manner and accessible to the individual • Awareness of symptom progression at end-of-life • Consistent, joined up care – a pathway connecting physical and mental health services	• Prognostication – clinician and patient perspectives • Models of care • Future care planning • How to prepare carers for what might happen at end-of-life

There's something about knowing what might happen but also that you would have support for when that happens.

How we view future care planning: aligning people's wishes in changing prognosis landscape.

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Please post any questions using the Q&A function

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