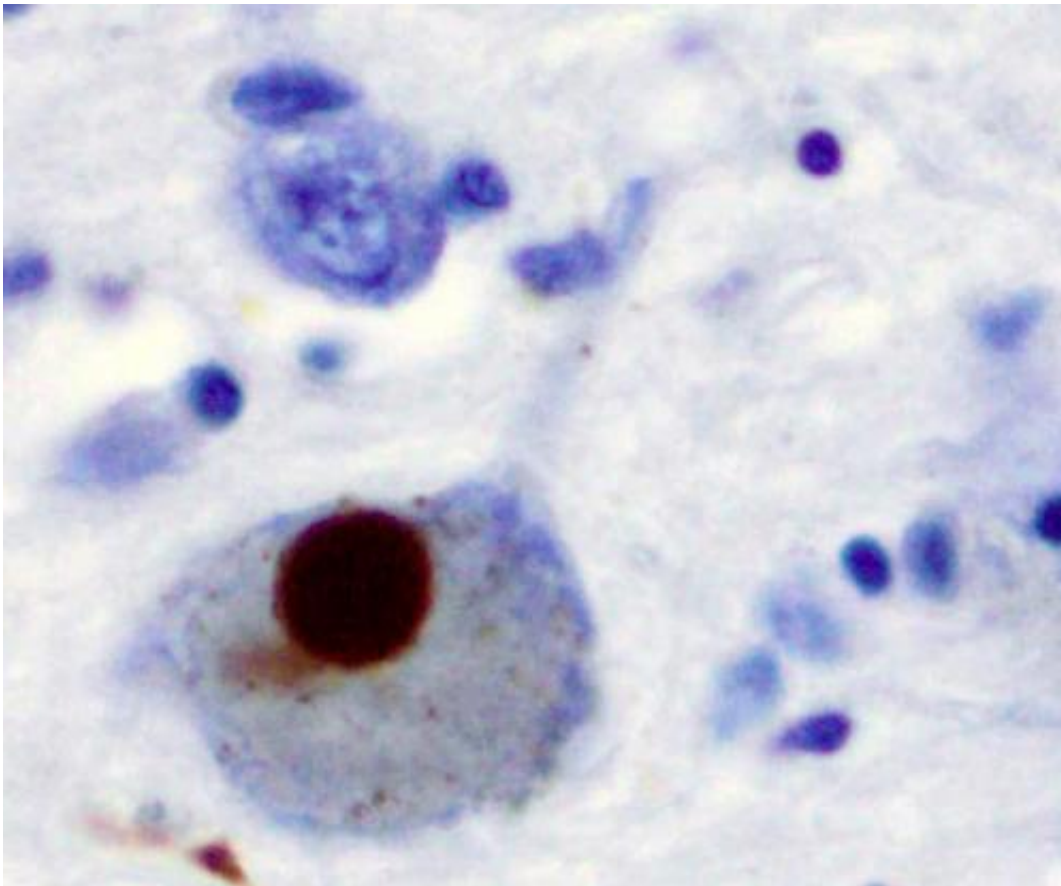


Parkinson's patients identify balance and anxiety among top 10 research priorities

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Immunohistochemistry for alpha-synuclein showing positive staining (brown) of an intraneural Lewy-body in the Substantia nigra in Parkinson's disease. Credit: Wikipedia

Patients with Parkinson's, medics and carers have identified the top ten

priorities for research into the management of the condition in a study by the University of East Anglia and Parkinson's UK.

Commissioned by Parkinson's UK, people with direct and indirect personal experience of the condition worked together to identify crucial gaps in the existing evidence to address everyday practicalities in the management of the complexities of Parkinson's. Patients stated that the overarching research aspiration was an effective cure for Parkinson's but whilst waiting for this more research was needed into the management of the condition.

Top of the list, which was narrowed down from a list of 94 uncertainties, was the need to identify what treatments help reduce [balance problems](#) and falls in people with Parkinson's.

This was followed in second place by questioning what approaches are helpful for reducing stress and anxiety in patients, and what treatments help reduce involuntary movements - a side effect of some medications - in third place.

Also outlined in the top ten research priorities for Parkinson's management, published today on *BMJ Open*, are better monitoring methods, improving sleep quality and the need to develop interventions specific to the different types of Parkinson's and the dementia that can be associated with Parkinson's.

Dr Katherine Deane, lead researcher from the University of East Anglia, said: "Ensuring that research is effective in addressing the needs of patients and the clinicians treating them is critically important, and the priorities will inform the research plans and funding from Parkinson's UK and hopefully other funders."

"The research agenda has been accused of being overly influenced by the

pharmaceutical industry and of not addressing the questions about treatments that are of greatest importance to patients, their carers and clinicians. Research needs to focus on whether treatments are doing more harm than good, or whether one treatment is better than another, and ensure the outcomes reflect issues that have impact on the patient's wellbeing and participation.

"These priorities identify crucial gaps in the existing evidence to address everyday practicalities in the management of the complexities of Parkinson's, with an overarching research aspiration to work towards an effective cure for Parkinson's."

One thousand participants provided initial ideas on research uncertainties, which were narrowed down to 94 unique ideas, which 475 participants used to select their own top ten priority list. A final 26 top priorities were then examined by 27 stakeholders who agreed a final top 10. People with Parkinson's were in the majority in all of these groups.

Arthur Roach, Director of Research and Development at Parkinson's UK, said: "This study highlights the very important fact, sometimes overlooked, that for many people with Parkinson's the most troublesome problems are not the classical motor symptoms, but things like sleep, falls, anxiety and difficulties with thinking. Ensuring that research meets the needs of people with Parkinson's is key and we will be using this awareness to guide our research programme in the future."

The project was led by Parkinson's UK, with the University of East Anglia and the University of Birmingham acting as academic partners. The James Lind Alliance provided an independent chair, advised on the methodology, and facilitated the process.

Overarching research aspiration: An effective cure

for Parkinson's

The top ten research priorities for the management of Parkinson's:

1. What treatments are helpful for reducing balance problems and falls in people with Parkinson's?
2. What approaches are helpful for reducing stress and anxiety in people with Parkinson's?
3. What treatments are helpful for reducing dyskinesias ([involuntary movements](#), which are a side effect of some medications) in people with Parkinson's?
4. Is it possible to identify different types of Parkinson's, eg, tremor dominant? And can we develop treatments to address these different types?
5. What best treats dementia in people with Parkinson's?
6. What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?
7. What is the best method of monitoring a person with Parkinson's response to treatments?
8. What is helpful for improving the quality of sleep in people with Parkinson's?
9. What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?
10. What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?

Provided by University of East Anglia

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