

MY PD JOURNEY

POSITIVE PROGRESS FOR
PEOPLE WITH PARKINSON'S



THE PARKINSON'S DISEASE COMPOSITE SCALE

WHAT IS MY PD JOURNEY?

A multi-stakeholder European coalition led by the European Parkinson's Disease Association (EPDA).

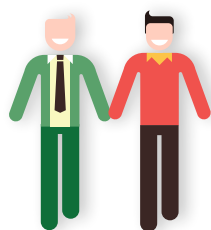


WHAT IS THE PARKINSON'S DISEASE COMPOSITE SCALE?

The My PD Journey coalition, on behalf of the EPDA, has developed the Parkinson's Disease Composite Scale (PDCS) – a simple new scale that measures the severity of symptoms experienced by people with Parkinson's in a timely way. It provides a comprehensive overview of motor and non-motor symptoms and enables clinicians to continually monitor the individual's condition.

WHY DEVELOP A NEW PARKINSON'S SCALE?

Existing scales used by neurologists currently explore different aspects of Parkinson's, but do not offer a comprehensive overview of the individual's condition. The development of the new PDCS was therefore urgently needed as it combines motor symptoms, non-motor symptoms and treatment-related complications; it is also simple and relatively fast to use. Crucially, it is designed to complement – rather than replace – existing scales by offering a comprehensive view of Parkinson's. In addition, it grades the relative importance of particular symptoms, taking into account people with Parkinson's perspectives, which are critical in the delivery of timely and effective treatment and care.



WHO LED THE DEVELOPMENT OF THE PDCS?

The development of the PDCS was led by Parkinson's specialist neurologists Pablo Martinez Martin (Spain), Fabrizio Stocchi (Italy) and Fabiana Radicati (Italy) in collaboration with the My PD Journey coalition.

WHO IS IT FOR?

The PDCS was designed as a tool to be used primarily by neurologists and other healthcare professionals familiar with Parkinson's. It is not a tool for self-assessment, but can help people with Parkinson's to better understand the complexity of their condition.



WHAT DOES IT MEASURE?

The PDCS measures motor symptoms, such as tremors, rigidity, bradykinesia and postural instability, as well as non-motor symptoms, such as depression, anxiety and urinary problems.



The PDCS also grades the relative importance of particular symptoms, taking into account patient perspectives, which are important in the delivery of timely and effective treatment and care.

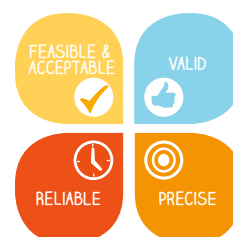
HOW SHOULD THE PDCS BE USED?

The PDCS should be used in clinical settings and can be conducted in roughly 15 to 20 minutes, as such freeing up time within the consultation to discuss other things important to the individual.

HOW AND WHEN WILL THE PDCS BE VALIDATED?

Work began on the PDCS in September 2014.

The initial pilot study and a first validation study were completed in 2015. The first validation study indicated that the scale was a feasible, acceptable, reproducible, valid and precise instrument for a more comprehensive measurement of Parkinson's symptoms. A second and more extensive validation study, aimed at reaffirming the first study's findings, was completed in July 2018 and is currently awaiting publication. This study involved 22 centres and 700 patients across 14 countries.



In parallel, My PD Journey is working with neurological and clinical bodies, policymakers, and patient organisations to promote the use of this new innovative tool across Europe.

HOW CAN I LEARN MORE?

My PD Journey is a first-of-its-kind multi-stakeholder project for people with Parkinson's in Europe, led by the EPDA. The Parkinson's Disease Composite Scale (PDCS) is a My PD Journey project, and as such belongs to the EPDA.

Visit www.epda.eu.com for more information about Parkinson's disease and the EPDA work programme. For more information on the Parkinson's Disease Composite Scale (PDCS), go to parkinsonscompositescale.com or email secretariat@mpdj.eu.

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