

Plotting a Better Pathway for Parkinson's Disease: A New Composite Scale from My PD Journey



Authors:	Lizzie Graham, Christian Jebsen, *Emily Ritchey My PD Journey Secretariat *Correspondence to secretariat@mpdj.eu
Disclosure:	The authors have declared no conflicts of interest.
Received:	21.10.16
Accepted:	09.04.18
Keywords:	Care pathways, clinical scale, diagnosis, disease management, Parkinson's disease (PD).
Citation:	EMJ. 2018;3[2]:12-15.

A clinical scale that takes a broader, deeper view of Parkinson's disease (PD) symptoms is the latest milestone in a collaborative effort by My PD Journey, a multi-stakeholder initiative led by the European Parkinson's Disease Association (EPDA). My PD Journey aims to address challenges to timely, comprehensive, and individualised management of PD in Europe by measuring motor and non-motor symptoms.

Project leaders Prof Fabrizio Stocchi, San Raffaele University and Institute for Research and Medical Care, Rome, Italy, and Prof Pablo Martinez-Martin, Carlos III Institute of Health, Madrid, Spain, presented the aims and characteristics of the composite scale, as well as results from the first validation studies using the new model, to political stakeholders at a PD summit at the European Parliament on 18th February 2016. The results of the first validation study were published in January 2018 and concluded that the Parkinson's Disease Composite Scale (PDCS) appears to be a feasible, acceptable, reproducible, and valid scale for disease management.¹ A second and more extensive validation study, aimed at reaffirming the first study's findings, is currently underway. This paper will later outline the PDCS in more detail.

WHERE IT ALL BEGAN

The inspiration for the My PD Journey project developed from the widespread frustration in the PD community at the low levels of political awareness of PD as a health priority in Europe and the resulting absence or slow implementation of policies and initiatives to drive change at regional and national levels. For a disease that affects >1.2 million people across Europe,² a figure set to double by 2030 as the population ages,³ the extent of this neglect is alarming. It is also costly: the annual financial burden of PD on the European economy has already reached at least €13.9 billion.² EPDA President, Knut-Johan Onarheim commented at a summit in February 2016 that these statistics "paint a bleak picture of the situation in Europe, especially considering the fact that the figures we do have are many years out of date." Mr Onarheim called for urgent collective action "on all fronts", with an emphasis on halting or slowing disease progression and improving PD patients' quality of life.

HURDLES TO DISEASE MANAGEMENT

People with PD face a number of hurdles to effective management of their disease, including inconsistent access to PD experts and delayed diagnosis. These delays can take

over a year; far longer than the maximum of 6 weeks recommended in clinical guidelines. The EPDA works to remove these hurdles by interacting closely with its member associations and engaging with European policymakers and other PD stakeholders. The EPDA also seeks to raise public awareness of PD as a key health challenge, support the development of national PD organisations across Europe, and eliminate the stigma and discrimination faced by people with the disease.

MY PD JOURNEY: A FIRST-OF-ITS-KIND MULTISTAKEHOLDER INITIATIVE

My PD Journey involves representatives from across the whole of the PD community, including umbrella European healthcare organisations, PD specialists, people with PD, carers, treatment industry companies, and members of the multidisciplinary healthcare teams managing the condition. The overarching objective is to create a sustainable environment in which people with PD have optimal and timely access to appropriate diagnosis, treatment, and care throughout the course of the disease. The scheme recognises their personal PD journey and the need for tailored disease management that will enable the patient to live as full a life as possible. My PD Journey has pioneered two flagship projects: pan-European research, completed in 2015, and the new PDCS.

THE EUROPEAN INVENTORY: GAINING A MORE ACCURATE INSIGHT INTO THE CHALLENGES FACING PATIENTS AND HEALTHCARE SYSTEMS

In November 2014, My PD Journey embarked on its first major phase of activity, the European inventory. This research project was a collaboration between the EPDA and the European Section of the International Parkinson and Movement Disorder Society (MDS-ES). As a result of this collaboration, care pathways for PD across Europe were assessed and compared with the goal of understanding the major hurdles to effective PD management, identifying gaps in existing care pathways, and finding examples of good national practice that could be replicated elsewhere.

Millbank Social Marketing Ltd., Cleveland, UK, was commissioned to conduct primary and secondary research for the project. This comprised a survey of 1,776 participants across 11 European countries, including people with PD, their carers, and healthcare professionals, followed by 194 in-depth interviews.⁴

The research was completed in 2015 and fed into recommendations for good practice in PD management at a national and European level that were presented at a landmark event in Brussels, Belgium, on 14th April 2015. Hosted by the Vice-President of the European Parliament, Mairead McGuinness, the workshop gathered stakeholders from across the entire PD community, as well as high-level representatives from the European Union (EU) institutions. These recommendations included:

- Timely diagnosis, access to specialised healthcare professionals, and continued management of the disease by a multidisciplinary team of experts.
- A personalised approach, reflecting the complexity of the disease and the crucial importance of tailoring treatment and care to individual needs and preferences.
- Patient and carer access to a PD healthcare professional trained to monitor and manage disease progression.
- Significant improvements in co-ordination and communication, particularly between primary and secondary healthcare professionals.
- Better PD training for healthcare professionals working in nursing homes and general hospital wards.
- All relevant information on the management and treatment of the disease should be available to people with PD and their carers.

POLICY RECOMMENDATIONS

The research findings from the European inventory also fed into a number of policy recommendations for EU and national member-state authorities, including EU support and funding for projects, such as My PD Journey; pooling of information and knowledge through reference networks; and support for further data collection to better inform diagnosis, treatment and care strategies. Since the event, the EPDA has engaged directly with influential EU

decision-makers in Brussels to advocate My PD Journey's policy recommendations and achieve concrete outcomes at a pan-European level. The political response to My PD Journey has been extremely positive, and European policymakers are starting to understand the challenge of PD. From these recommendations and meetings, the EPDA developed its EU political manifesto.

THE COMPOSITE SCALE: IMPROVING DIAGNOSIS AND DISEASE MANAGEMENT

The My PD Journey composite scale brings these efforts down to the practical level, with a tool to help doctors and people with PD tackle one of the earliest barriers to properly tailored and balanced management of the disease. It is designed to complement existing clinical scales, which the My PD Journey European Strategic Committee (ESC) felt could not measure and rate PD symptoms in a way that reflects the full complexity and scope of the condition.

The effects of PD on motor functions are generally well recognised, including tremors, rigidity, bradykinesia, and postural instability. However, there is less awareness of non-motor symptoms, such as depression, anxiety, sexual dysfunction, constipation, or urinary problems, and the magnitude of their physical, psychological, and cognitive impact on patients, families, carers, and healthcare systems.

The full breadth of PD symptoms may be difficult to express, capture, and track within the confines of a 10-15-minute doctor's appointment. The situation is aggravated by the present need to use several rating scales, such as UPDRS, NMS, UDysRS, mAIMS, and MoCa, when assessing disease severity. Not only are standard assessments designed for other conditions and not sensitive enough to give a full picture of PD, but health and regulatory authorities now demand objective measures when allocating budgets for different diseases. As things stand, a straightforward holistic scale to evaluate the status of PD patients that takes into account both motor and non-motor symptoms, as well as treatment complications and disability level, does not exist. The lack of such a scale

represents a significant obstacle to timely and appropriate interventions that will optimise the management of PD.

PARKINSON'S DISEASE COMPOSITE SCALE

The development of such a straightforward, holistic scale was the thinking behind the PDCS, a project spearheaded by Prof Fabrizio Stocchi, and Prof Pablo Martinez-Martin.

The aim was to develop a new, easy-to-use clinical scale that would not replace, but work in concert with, existing instruments. These latter scales remain crucial to the precise assessment of certain PD symptoms (e.g., NMS for non-motor symptoms and UDysRS for dyskinesia). At the same time, the PDCS would provide a more comprehensive overview of patient status, including quality of life considerations and the relevance of particular symptoms to healthcare systems as well as patients themselves. For example, tremors may be a significant feature of PD for patients in terms of day-to-day activities, self-confidence, and stigmatisation. They may be less of an issue for healthcare systems with respect to disease management and associated costs. By the same token, a patient falling down can have a substantial impact from both perspectives.

The PDCS was designed to incorporate the most important motor, non-motor, and treatment-complication symptoms of PD. These are symptoms identified through expert experience and patient reports as more significant in determining disease severity. The composite scale also tried to give different weight to different symptoms, according to their impact on quality of life. PDCS also needed to be straightforward enough to be understood by all healthcare professionals addressing PD, as well as by PD patients themselves.

Developing the Scale

Initial work on the PDCS began in September 2014. A pilot study involving 70 patients with mild-to-moderate PD produced satisfactory outcomes in terms of the tool's acceptability and hypotheses-testing.¹ These tests highlighted some problems of internal consistency that were further assessed in the first validation

study of the composite scale. This multicentre study involved a total of 194 PD patients, with a mean age of 66.51 years, in five countries (Australia, Italy, Romania, Sweden, and the UK). It looked at:

- Feasibility and acceptability: The extent to which the PDCS could be used successfully in a clinical setting.
- Reliability (internal consistency and stability): How much the scale was free from random errors.
- Validity (hypothesis-testing validation): The extent to which the scale assessed the underlying theoretical construct it was designed to measure.
- Precision: The scale's ability to distinguish between small differences in symptoms.

The validation study indicated that the PDCS was a feasible, acceptable, reproducible, valid, and precise instrument for more holistic measurement of PD symptoms.

Given the pragmatic characteristics of the scale, the EPDA and the scale's developers proposed a second, larger validation study to confirm the initial findings and promote a broad use of the PDCS. This second study, due to be finalised and published in 2018, is being co-ordinated by Fabiana Giada Radicati at the IRCSS San Raffaele, Rome, Italy. There are 22 centres

participating in the second validation study from 14 countries, involving around 700 patients. The My PD Journey team is currently working with neurological and clinical bodies, policymakers, and patient organisations to roll out this new tool across Europe, and beyond.

THE JOURNEY CONTINUES

My PD Journey will continue to work with stakeholders at all levels of PD diagnosis and management to improve patient outcomes by designing, implementing, evaluating, and optimising patient-centred care models for this life-changing disease. My PD Journey strives to publish all the European inventory research and composite scale studies in peer-reviewed journals, while exploring options for further data collection and analysis and ensuring the roll-out of the composite scale in clinical and patient settings across Europe.

With the support and encouragement from healthcare professionals, research funders, PD experts, policy makers, and the general public, the coalition can leverage the benefits of collaborative efforts across national, cultural, and professional boundaries, to ensure that living with PD means a life both lived to the full and integrated as much as possible with healthcare practices and society as a whole.

References

1. Stocchi F et al. The Parkinson's Disease Composite Scale: Results of the first validation study. *Eur J Neurol.* 2018;25(3):503-11.
2. Gustavsson A et al.; CDBE2010 Study Group. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol.* 2011;21(10):718-79.
3. Dorsey ER et al. Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030. *Neurol.* 2007;68(5):384-6.
4. Schrag A et al. Patient experiences of receiving a diagnosis of Parkinson's disease. *J Neurol.* 2018:1-7. [Epub ahead of print].