

Plotting a better pathway for Parkinson's disease: the My PD Journey project

A [clinical scale](#) that takes a broader, deeper view of PD symptoms is the latest milestone in a collaborative effort to resolve multiple challenges to timely, comprehensive and individualised management of Parkinson's disease across Europe.

Project leaders Professor Fabrizio Stocchi and Professor Pablo Martinez-Martin presented the aims and characteristics of the My PD Journey composite scale, as well as results from the first validation studies with the new model, to political stakeholders at a Parkinson's disease summit in the European Parliament on 18 February (see [press release](#) here).

The summit and the progress made with the composite scale testify to the strong momentum behind the My PD Journey project, launched in 2014. It is led by the European Parkinson's Disease Association (EPDA), an umbrella group representing over 250,000 members in nearly 30 countries whose mission is to advocate for the rights and needs of more than 1.2 million people with Parkinson's and their families in Europe.

In April 2015, the My PD Journey coalition presented 14 European and national policy recommendations to improve the diagnosis, management and outcomes of Parkinson's disease at a workshop in Brussels, Belgium, attended by high-level EU officials and stakeholders from around Europe.

These recommendations, which take in access to individualised treatment and care, appropriate referrals to specialised healthcare professionals, PD training and education, data collection, and patient information, were the fruits of My PD Journey's first large-scale initiative, the [European inventory](#).

HOW IT STARTED

The spur for My PD Journey was frustration in the Parkinson's community at the persistent low level of political awareness in Europe around PD as an urgent health priority, and the resulting absence or slow implementation of policies and initiatives to drive change at regional and national level.

For a disease that affects more than 1.2 million people across Europe¹, a figure set to double by 2030 as populations age², this kind of neglect is alarming. It is also costly: the annual financial burden of Parkinson's on the European economy has already reached at least €13.9 billion³.

As EPDA President Knut-Johan Onarheim commented at last February's summit, 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".

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 MANAGEMENT

People with Parkinson's face a number of hurdles to effective management of their disease, including inconsistent access to Parkinson's experts and delayed diagnosis, which can take well over a year – far more than the maximum six weeks recommended in clinical guidelines.

Compounding these problems is lack of communication between primary and secondary healthcare providers, which frustrates efforts to draw up consistent, regular and cohesive care plans for Parkinson's patients.

The EPDA works to remove these hurdles by interacting closely with its [member associations](#) and engaging with European policy makers as well as other Parkinson's stakeholders.

It also seeks to raise public awareness of Parkinson's as a key health challenge, support the development of national Parkinson's organisations across Europe, and eliminate the stigma and discrimination faced by people with the disease.

1 Andlin-Sobocki 2005

2 Dorsey 2007

3 Cost of the Brain in Europe" Eur (Neurol 2005; 12 (Suppl 1: 1-27)

MY PD JOURNEY – A FIRST-OF-ITS-KIND MULTI-STAKEHOLDER COALITION

The My PD Journey initiative involves representatives from across the whole of the Parkinson's disease community, including umbrella European healthcare organisations, PD specialists, people with Parkinson's, 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 Parkinson's have optimal and timely access to appropriate diagnosis, treatment and care throughout the course of the disease - recognising their personal PD journey and the need for tailored disease management that will enable them to live as full a life as possible.

THE EUROPEAN INVENTORY

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 International Parkinson and Movement Disorder Society European Section. It assessed and compared different care pathways for Parkinson's across Europe, with the goal of understanding 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 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 Parkinson's, their carers and healthcare professionals, followed by 194 in-depth interviews.

The research was completed in 2015 and the My PD Journey working group developed the following six recommendations as a focus for good practice in PD management at national and European level:

- Timely access to specialised healthcare professionals, including referrals within six months; diagnosis by a neurologist or a doctor with a special interest in Parkinson's; and continued management and review 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, who should be a continuing point of contact for information about clinical and social issues as well as support where appropriate.
- Significant improvements in co-ordination and communication, particularly between primary and secondary healthcare professionals. At the same time, monitoring methods should be developed to ensure that Parkinson's care plans remain consistent, regular and cohesive.
- Better Parkinson's 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 Parkinson's and their carers. In particular, they should be able to ask for:
 - an appointment with a healthcare professional within two weeks of the initial diagnosis, where possible;
 - information on relevant support organisations and services.

POLICY RECOMMENDATIONS

The research findings from the European inventory also fed into a number of policy recommendations for EU and national member-state authorities.

The inventory findings and recommendations were presented at a landmark event in Brussels on 14th April 2015. Hosted by Vice-President of the European Parliament Mairead McGuinness MEP, the workshop gathered stakeholders from across the entire Parkinson's community, as well as high-level representatives of the EU institutions.

Participants discussed a number of policy recommendations, 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 for My PD Journey's policy recommendations and achieve concrete outcomes at a pan-European level (more information available [here](#)). The political response to My PD Journey has been extremely positive, and European policymakers are starting really to understand the challenge of PD.

At a national level, the My PD Journey coalition is also calling on Member State governments to

- Implement early intervention strategies and support funding to ensure timely diagnosis and appropriate management of people with Parkinson's.
- Develop policies and incentives for the provision of support programmes to carers managing Parkinson's disease.

- Support and develop Parkinson's-related training programmes for healthcare professionals working in nursing homes and general hospital wards.
- Foster development of multidisciplinary partnerships between healthcare providers, community and health planners, patients and carers to encourage integration of care and good-practice sharing.
- Develop and encourage monitoring methods to ensure that people with Parkinson's receive appropriate diagnosis, management and support throughout their disease journey.
- Develop policies and incentives to promote training and involvement of healthcare professionals specialising in Parkinson's disease management.
- Support and fund national Parkinson's registries to improve understanding and measurement of the PD disease burden for healthcare systems and society.
- Develop or update national guidelines to support clinical decision-making in terms of:
 - Parkinson's diagnosis;
 - information provision to patients;
 - timely and appropriate referral and access to expert healthcare professionals;
 - a personalised approach to Parkinson's-disease treatment and use of the latest available technologies;
 - better communication between primary and secondary healthcare professionals.

Most of these government initiatives should be undertaken in co-operation with key stakeholders in Parkinson's-disease management, My PD Journey proposed.

THE COMPOSITE SCALE

The European inventory initiative was about understanding the overall landscape for PD management, identifying where current practice was falling short, and making policy recommendations to address those deficits.

The My PD Journey composite scale brings these efforts down to the practical level, with a tool to help doctors and people with Parkinson's tackle one of the earliest barriers to properly tailored and balanced management of the disease.

This is the inability of existing clinical scales to measure and rate PD symptoms in a way that reflects the full complexity and scope of the condition.

The effects of Parkinson's on motor functions are generally well recognised: tremors, rigidity, bradykinesia and postural instability among them.

There is less awareness, though, 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 Parkinson's symptoms may be difficult to express, capture and track within the confines of a 10- or 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, not sensitive enough to give a full picture of Parkinson's, 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, one that takes into account both motor and non-motor symptoms, as well as treatment complications and disability level, simply does not exist.

That represents a significant obstacle to timely, appropriate interventions that will optimise the management of Parkinson's.

MORE COMPREHENSIVE OVERVIEW

This was the thinking behind the Parkinson's Disease Composite Scale (PDCS), a project spearheaded by Professors Fabrizio Stocchi from the San Raffaele University and Institute for Research and Medical Care in Rome, Italy; Pablo Martinez-Martin from the Carlos III Institute of Health in Madrid, Spain; and Ray Chaudhuri of Kings College, London, UK.

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 Parkinson's symptoms (e.g., NMS for non-motor symptoms, UDysRS for dyskinesia).

At the same time, the PDCS would provide a more comprehensive overview of patient status, including quality-of-life (QoL) considerations and the relevance of particular symptoms to healthcare systems as well as patients themselves.

For example, tremors may be a significant feature of Parkinson's 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 Parkinson's disease. 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 QoL.

It also needed to be straightforward enough to be understood by all healthcare professionals addressing Parkinson's disease, and by people with Parkinson's themselves.

DEVELOPING THE SCALE

Initial work on the PDCS began in September 2014. A pilot study in 70 patients with mild-to-moderate Parkinson's produced satisfactory outcomes in terms of the tool's acceptability and hypotheses-testing.

It also highlighted some problems of internal consistency that were further assessed in the first validation study of the composite scale.

This multi-centre 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 United Kingdom). 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 Parkinson's Disease Composite Scale was a feasible, acceptable, reproducible, valid and precise instrument for more holistic measurement of PD symptoms. Once finalised, the PDCS will be rolled out across Europe.

NATIONAL COALITIONS

The third major strand of the My PD Journey project, one that is ongoing, is encouraging Parkinson's stakeholders to form [national coalitions](#) that can help to implement some of the solutions emerging from other areas of the initiative.

These national coalitions will establish their own tailored models of comprehensive Parkinson's care that reflect unique challenges in their national healthcare systems. The coalitions involve a wide range of stakeholders from across the Parkinson's community, including EPDA member organisations, specialist neurologists, patients, carers, hospital managers, industry partners and national, regional or local politicians.

So far, nine coalitions have been set up⁴. These have already begun to address some of the key hurdles identified in the European inventory research. The hope is that, where national coalitions are successful in resolving these issues, their activities can be scaled up and/or extended to other European countries facing similar problems.

THE JOURNEY CONTINUES

My PD Journey will continue to work with stakeholders at all levels of Parkinson's diagnosis and management to improve patient outcomes by designing, implementing, evaluating and optimising patient-centred care models for this life-changing disease.

With 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 Parkinson's means a life both lived to the full and integrated as much as possible with healthcare practices and society as a whole.

4 Belgium, Denmark, Finland, Greece, the Netherlands, Norway, Spain, Sweden, the UK