

Parkinson's Disease Composite Scale usage and translation guidelines

June 2020

Introduction

Developed by the *My PD Journey* coalition – a multi-stakeholder European coalition led by the EPDA – the Parkinson's Disease Composite Scale (PDCS) is a simple new rating scale to be used primarily by neurologists and other healthcare professionals familiar with Parkinson's that measures the severity of *symptoms* experienced by people with Parkinson's in a timely way.

We are calling on healthcare professionals to use the scale and provide feedback, as we seek to increase uptake of the PDCS across Europe.

Background

Most existing *rating scales* used by neurologists currently explore different aspects of the condition, but do not offer a comprehensive view of a person's condition quickly. The development of the new PDCS, led by Professors Fabrizio Stocchi (Italy), Fabiana Radicati (Italy) and Pablo Martinez Martin (Spain), was therefore urgently needed as it combines *motor symptoms*, *non-motor symptoms* and treatment-related *complications*. The PDCS is designed to complement existing scales – not to replace them – and is simple and relatively fast to use.

Validation

- The *results of the first validation study* were published in January 2018 in the *European Journal of Neurology*. Results of the study concluded that the PDCS appears to be a feasible, acceptable, reproducible and valid scale.
- A second and more *extensive validation study*, aimed at reaffirming the first study's findings, was completed in July 2018 and published in April 2019. This study involved 22 centres and 700 patients across 14 countries.

Guidelines for usage

Thank you for your interest in using the PDCS in your clinical/research practice.

The PDCS is free to use and disseminate for all healthcare professionals working with people with Parkinson's.

When using the PDCS, we kindly ask you to comply to the following guidelines:

- you will call it 'the Parkinson's Disease Composite Scale' at all times;
- you will (where relevant) explain that it is the EPDA's rating scale;
- you will (where relevant) include the relevant EPDA website links (www.parkinsonscompositescale.com and/or <https://www.epda.eu.com/pdcs/>) as a source for others to refer to;
- you will always officially share your feedback with us (via email contacting francesco@epda.eu.com) about your experience of using the PDCS – and also about the experience of the person(s) with Parkinson's;
- if you have a good experience of using the PDCS, you will promote the scale via social media and other communication channels (such as, for example, your own blog or website) as much as possible, using the appropriate social media hashtags: **#PDCS #ParkinsonsDiseaseCompositeScale #MyPDJourney**
- you will generally follow the EPDA [copyright guidelines](#) established for EPDA content.

If you have any questions, please contact us at francesco@epda.eu.com.

Guidelines for translation

The PDCS has been developed and validated in English by the study group.

However, we are aware that healthcare professionals from countries where English is not the primary language may be in the necessity to translate the PDCS in order to be able to use it effectively in their own clinical practice.

In order to ensure that each version of the PDCS translated into different languages is appropriately validated, any translation must follow a protocol to guarantee the equivalence between the original and the translated version.

If you would like to translate the PDCS into a language different than English, we therefore recommend you follow the following guidelines developed by the World Health Organisations (WHO):

- WHO, [Process of translation and adaptation of instruments](#)

For additional useful information and guidance on the process to follow to translate clinical instrument, please see the following resources:

- Goetz C G, Stebbins G T, Wang L, LaPelle N R, Luo S, Tilley B C, *Sponsored Scale Translation Program: Process, Format, and Clinimetric Testing Plan for the MDS -UPDRS and UDysRS*. Movement Disorders 2014. Vol. 1(2); 97-101 – <https://doi.org/10.1002/mdc3.12023>

- Gjersing L, Caplehorn J RM, Clausen T, *Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations*. BMC Medical Research Methodology 2010. Vol. 10(13) – <https://doi.org/10.1186/1471-2288-10-13>
- Martínez-Martín P, *Cross-Cultural Adaptation – Guidelines*, 2008

Once you have translated and validated the PDCS in your own language according to the process above, we kindly ask you to share the translated version with us – we will then make it available together with the original English version via the www.parkinsonscompositescale.com website.

If you have any questions, please contact us at francesco@epda.eu.com.