

European Guideline for physiotherapy in Parkinson's disease

Newsletter 4, June 2012



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What has been done the past months?

- Data survey (3,405 participants) exported, translated and cleaned
- Literature systematically searched, selected, data extracted & critically appraised
- Interventions and measurement tools categorised by Writing Group
- First conclusions drawn

Upcoming dates	June 2012	Reading Group members contacted for feedback
	July 2012	Pre-final draft for review to Review Panel and ES Movement Disorders
	September 2012	Guideline finished

Introduction of Steering Group members

After introduction of the Writing and Reading Group members in foregoing newsletters, we now would like to introduce the Steering Group members to you. The Steering Group members support and advise us in the process of the guideline development, e.g. looking at the methods, timeline, and incorporation of required persons (for both a patient and therapists perspective). Therefore, members of the Steering Group are of a variety of backgrounds:



Dr. Anna Jones, Representative of the APPDE
Anna (Diana) Jones, a neurological physiotherapist by background, is a Principal Lecturer in the School of Health, Community and Education Studies at Northumbria University, Newcastle upon Tyne (UK). Her research and PhD supervision is mainly focused on Parkinson's.



Dr. Philip van der Wees, Chair of the GIN
Philip, a physiotherapist by background, is program manager Quality & Implementation in a KNGF and two Dutch universities joint program. He chairs the Guidelines International Network. In 2011, he was awarded the Harkness Fellowship in Healthcare Policy and Practice.



Lizzy Graham, Representative of the EPDA
Lizzy Graham is the longest-serving ambassador of the European Parkinson's Disease Association, the patients' association. After having been secretary general for six years, since April 2012 she now is director of fundraising and global communications, an EPDA board member.



Prof. Alice Nieuwboer, Developer of the DVD accompanying the KNGF 2004 guideline
Alice, a physiotherapist by background, is program director, and teacher of undergraduate and postgraduate courses in rehabilitation science at the Faculty of Movement and Rehabilitation Sciences, KU Leuven (Belgium). Parkinson's disease is her main research interest.



Victorine De Graaf - Peeters, Representative of the KNGF
With a background in neuropsychology and nursing, Victorine is Senior Policy Advisor Science at the Royal Dutch Society for Physical Therapy (KNGF). She overlooks more than 80 projects, varying from research to monodisciplinary and multidisciplinary clinical guidelines and politics.



Bastiaan Bloem, ES-MDS executive committee
Bas is a consultant neurologist at the Radboud University Nijmegen Medical Centre. One of his main research interests is healthcare innovation, focussing on patient-centred, collaborative care. Together with Dr. Marten Munneke, he initiated the development of the KNGF 2004 guideline, as well as ParkinsonNet.

Survey answers translated and cleaned

In November 2011, the web-based European Survey was closed. Of the 9,646 physiotherapists addressed in 17 countries, 3,405 participated (35%). As answers provided to the survey were in as many as 11 languages, it had cost considerable time to have them exported and translated. *Many thanks to the representatives who have supported us in doing so!* We categorised the answers and finally cleaned all data. It was a time consuming process, for which we sincerely thank Frauke Burfeind in her support! Frauke has now moved back to Germany, where she is working as a physiotherapist and has started a training in osteopathy.

Survey benefits

The survey has given us great insight in the delivery of physiotherapy care in Parkinson's disease throughout Europe. Information that is essential to the development of the European guideline, but also information which can be used in each country to optimise this care. For example, we now have insight in the most frequently used measurement tools, interventions applied which are not yet described in the current KNGF guideline, and barriers for delivering optimal care.

The main conclusions of the survey results are presented on a poster, used for the 7th World Congress for NeuroRehabilitation in Melbourne, Australia (May 2012), available through the APPDE website: www.appde.eu/EN/european-guideline.asp. An article, to be submitted to an international peer-reviewed journal is now in preparation. All countries who participated in the survey will be contacted for this.

Search for evidence

In November 2011, we carried out the initial systematic literature search to identify controlled clinical trials on physiotherapy in Parkinson's disease. A total of 483 controlled clinical trials, 54 systematic reviews and 13 guidelines were identified through PubMed. The search strategy, based on the Cochrane and NICE searches, will be presented in the guideline. Of these publications, we first did a check on the titles, if necessary on abstracts, and finally full texts. Cross references were checked, as well as the PEDRO database and abstract books of recently held congresses. The overview of remaining publications on controlled clinical trials was shared with the Writing and Reading Group for feedback on adjustments and omissions. In addition, after publication of the updated Cochrane review on physiotherapy in Parkinson's disease (Feb 2012), an update of the literature search was carried out. Finally, 77 eligible controlled clinical trials were selected.



WG Group in Amsterdam; group photo, left to right: Marten Munneke, Susanne Brühlmann, Jan Prins, Josefa Domingos, Jaana Paltamaa, Bhanu Ramaswamy, Mariella Graziano & Samyra Keus (not in this photo Chris Struiksma & Elisa Pelosin)

Writing Group meeting

In February 2012, the 10 members of the Writing Group met in Amsterdam. Starting off with a meeting on Thursday night; all of Friday was used to discuss and work on the guideline together. A great opportunity, enormously supporting the collaborative work. Main steps taken were clustering and categorising, on categories of the ICF, of the measurement tools used in the selected publications, as well as a start of the categorisation of the interventions evaluated in these publications.

Appraising the evidence

Our next step was to extract data from the publications eligible for use in the guideline development. Next, these data needed to be appraised.

In critical appraisal systems used before (e.g. in the 2004 KNGF guideline), the quality of the evidence was appraised for single studies. With GRADE however, the body of evidence across studies, for a specific question (intervention & outcome) is appraised collectively. This was done for each of the key questions created, and based on the categorisation of the interventions evaluated. Only outcomes that are graded as important will be included. A difficulty in using the GRADE system is that it is easy to use when meta-analyses have been carried out. However, in our field, often this is not the case. Therefore, we also had to resort to a more qualitative appraisal of the evidence, using the key elements of GRADE. For most of the key questions, the evidence has now been appraised.

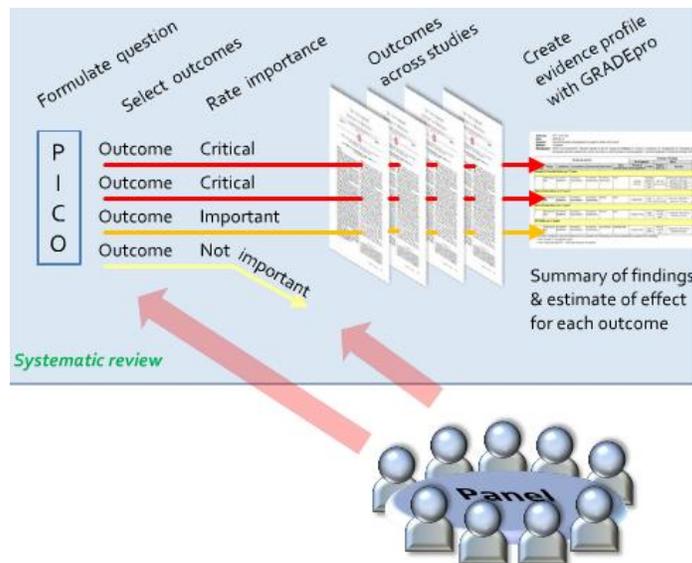


Figure: Holger Schönemann, McMaster University: <http://cebgrade.mcmaster.ca/Introduction/index.html>

Preparation conclusions

From the summary of findings, the WG is now working towards recommendations. In addition, the measurement tools selected for and described in the KNGF 2004 guideline is currently being updated and adjusted. Results from the current use of tools (EU survey) and new information from research is being used for this. At steps taken, the Reading Group members will be involved.

EPDA 2012 Unity Walk for Parkinson's

On 28 September coming, the next EPDA European Unity Walk will be held, in Amsterdam. A 1.6 kilometre long procession of persons with Parkinson's, their family, friends, healthcare professionals and other supports. With this unique event, the EPDA aims to 'to raise awareness across Europe about Parkinson's disease and its impact on people living with the disease, their families and our entire society'. We will be there. Will you be walking with us?

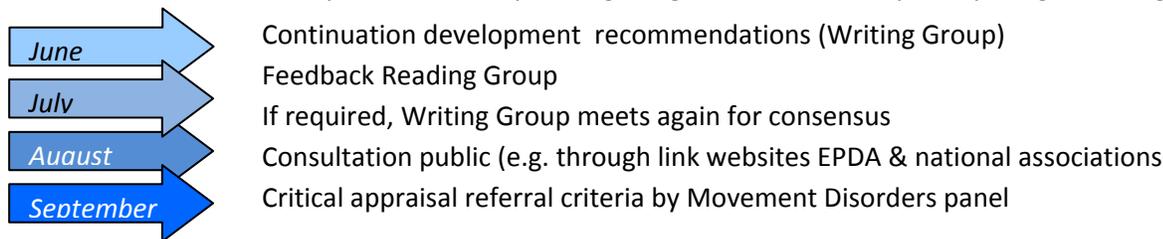
For more information please visit: www.epda.eu.com/en/events/european-unity-walk/#



Moving together for people with Parkinson's

Main activities until September 2012:

Given that we now are in the phase of actually writing the guideline, we will update you again in August



Stay informed: www.appde.eu/EN/european-guideline.asp