



The patient's perspective: First field study of a novel Parkinson's Disease Pain Questionnaire (King's PD Pain Quest)

Alexandra M Rizos¹, Pablo Martinez-Martin², Suvankar Pal³, Camille Carroll⁴, Davide Martino⁵, Belinda Kessel⁶, Antoniya Todorova¹, Anna Sauerbier¹, Anne Martin¹, Miriam Parry⁷, Sandeep Bassi¹, Rona Inniss¹, Panagiotis Zis¹, Per Odin⁸, Angelo Antonini⁹, Cristian Falup-Pecurariu¹⁰, K Ray Chaudhuri, DSc¹¹ on behalf of EUROPAR and the IPMDS Non-Motor PD Study Group

¹King's College Hospital, London, UK; ²National Center of Epidemiology and CIBERNED Carlos III Institute of Health, Madrid, Spain; ³Forth Valley Royal Hospital, Scotland, UK; ⁴Derriford Hospital, Plymouth, UK; ⁵Queen Mary's Hospital, Kent, UK; ⁶Princess Royal University Hospital, Orpington, UK; ⁷University Hospital Lewisham, London, UK; ⁸University of Lund, Lund, Sweden; ⁹University of Padua, Venice, Italy; ¹⁰Transylvania University, Brasov, Romania and ¹¹King's College London, King's College Hospital, University Hospital Lewisham, London, UK.

OBJECTIVE: To develop an "easy to use" novel clinical Parkinson's Disease (PD) specific pain questionnaire, complimentary to the King's PD Pain Scale, which can be completed by patients themselves.

BACKGROUND:

- Pain is an under-explored and poorly characterised non-motor symptom of PD and a major determinant of quality of life. ¹
- The first Parkinson's specific scale (King's PD Pain Scale) has been recently developed to characterise the various types of pain in PD and to allow for focused treatment.
- The first field testing of PD Pain Scale has been reported. ²
- To date, no specific **pain related self declaration tools** are available.

METHODS:

- A patient-completed questionnaire (King's PD Pain Quest) with simple "yes" or "no" answers to 14 questions was developed based on the King's PD pain scale, addressing the same items as the scale in simple English understandable by patients.
- In a cross-sectional, open, multicentre pilot study we collected data from PD patients with otherwise unexplained pain, as well as form controls without PD or other diagnosed disorders causing pain, to validate the King's PD Pain Quest.
- Recruitment target is 150 patients and 300 controls.

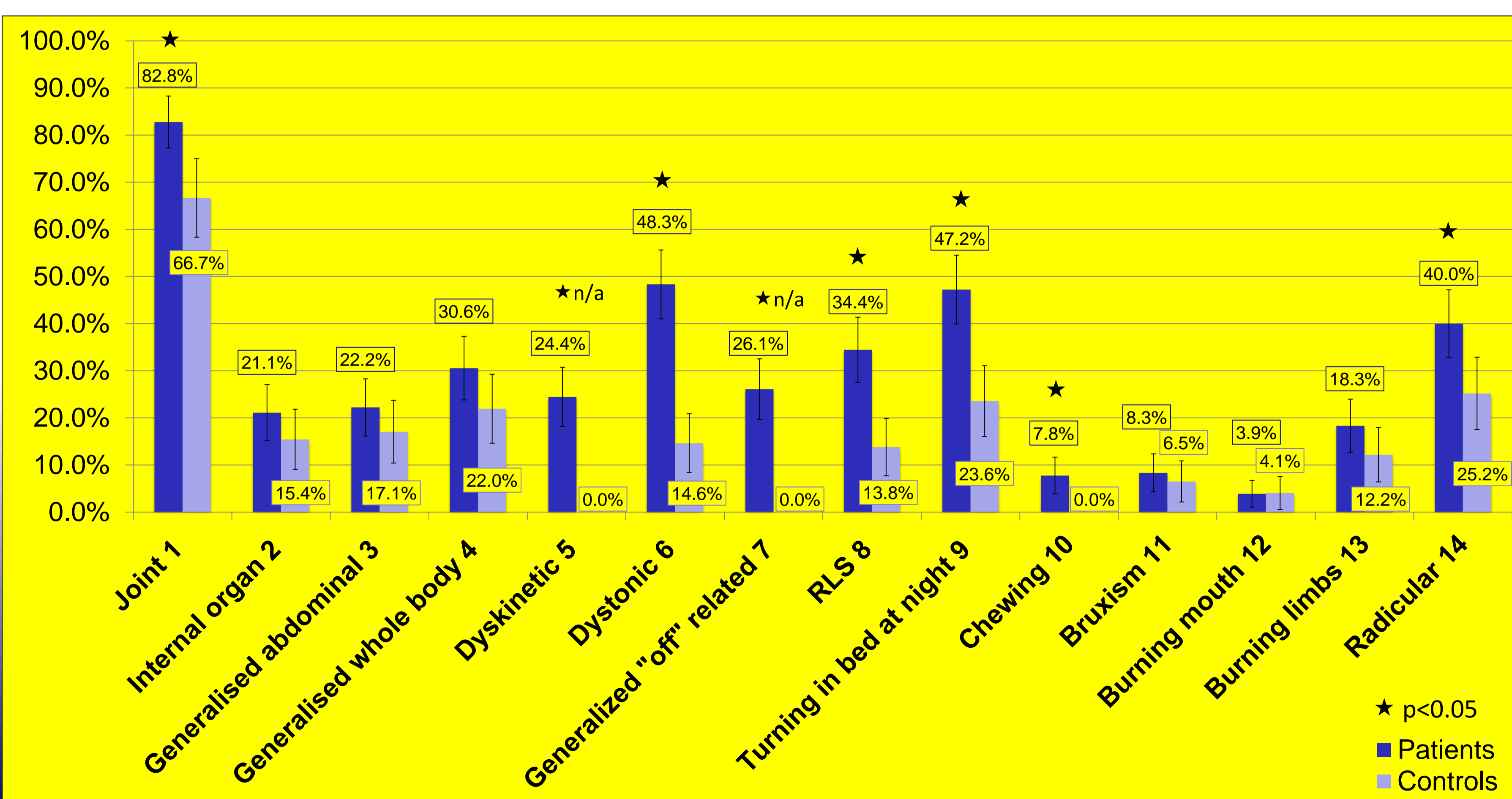
Demographics		Number/ mean (median)	Range/ %
Patients	Number (Males: Females)	180 (113: 67)	62.8%: 37.2%
	Age (yrs) ± SD	64.4±11.4	29 – 85
	Duration of Disease (yrs) ± SD	5.5±5.0	0 – 26
	Hoehn & Yahr Stage	2.0 (median)	1.0 – 5.0
Controls	No (Males: Females)	123 (72:51)	58.5%: 41.5%
	Age (yrs) ± SD	58.2±15.9	20 - 89

RESULTS 2:

- Differences between patients and controls reached significance level for musculoskeletal, dystonic, RLS related and radicular pain ($p < 0.05$, chi-square test).
- Dyskinetic and "off" related pain does not apply to non-PD controls and therefore were only assessed in patients.

RESULTS 1:

- We report data from 180 patients and 123 controls.
- In PD patients all assessed types of pain were present. Most frequent and least reported types of pain by patients and controls: see graph.



REFERENCES:

- 1 Wasner G, Deuschl G. Nat Rev Neurol. 2012;17(8):284–294
- 2 Rizos A et al. [abstract]. Mov Diso 2014;29 Suppl 1 :510

KING'S PD PAIN QUEST

Patient ID No: _____ Initials: _____ Date of birth: _____

Date of assessment: _____ Male Female Centre: _____

PAIN IN PARKINSON'S

The movement symptoms of Parkinson's are well known. However, other problems like pain can occur as part of the condition or its treatment. It is important that the doctor knows about the specific type of your pain, particularly if it is troublesome for you.

Several types of pain are listed below. Please:

- Tick the box "Yes" if you have experienced this particular type of pain during the past month.
 - If you have not experienced the type of pain in the past month tick the "No" box.
 - The doctor or nurse may ask you some additional questions to help you decide.
- Please note that this questionnaire only relates to the pain you experienced in the last 30 days.

HAVE YOU EXPERIENCED ANY OF THE FOLLOWING IN THE LAST MONTH?

- | | Yes | No |
|--|--------------------------|--------------------------|
| 1. Pain around the joints (including pain related to arthritis) | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Pain related to a specific internal organ (for example, pain around the liver, stomach or bowels) | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Generalised non-specific pain in your stomach area..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Non-specific pain deep within the body: a generalised constant, dull, aching pain..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Pain related to abnormal involuntary movements (dyskinetic pain) | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Painful muscle cramps in a specific region during "off" periods (when your medication is not working)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Generalised pain during "off" periods (pain in the whole body or areas that are not affected by muscle cramps)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Pain related to jerking leg movements during the night or an unpleasant burning sensation in the legs which improves with movement (restless legs syndrome) | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Pain related to difficulties when turning in bed at night | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Pain when chewing | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Pain related to grinding teeth during the night | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Burning sensation in your mouth..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Burning pain in the limbs (often associated with swelling or medication)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Shooting pain/pins and needles down the limbs | <input type="checkbox"/> | <input type="checkbox"/> |

ACKNOWLEDGMENTS: This poster presents independent research funded by the National Institute for Health Research (NIHR) Mental Health Biomedical Research Centre and Dementia Unit at South London and Maudsley NHS Foundation Trust and King's College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The authors of this poster have nothing to declare concerning this poster.

CONCLUSIONS: Interim results suggest the PD Pain Quest may be a useful self-completed tool complimentary to the PD pain scale for assessment of patient reported pain in PD.