



# The Parkinson's Disease Questionnaires

## User Manual

PDQ-39, PDQ-8, PDQ Summary Index & PDQ Carer

*Third Edition*

Crispin Jenkinson  
Ray Fitzpatrick  
Viv Peto  
Sarah Dummett  
David Morley  
Phil Saunders

# The Parkinson's Disease Questionnaires

## User Manual

(PDQ-39, PDQ-8, PDQ Summary Index & PDQ-Carer)

*Third Edition*

Crispin Jenkinson  
Ray Fitzpatrick  
Viv Peto  
Sarah Dummett  
David Morley  
Phil Saunders



Health Services Research Unit, University of Oxford

ISBN 1 874551 95 2

© 2012, Oxford University Innovation Limited

PDQ-39 and PDQ-8 © 1993, 1998 Oxford University Innovation Ltd. The technology transfer company of the University of Oxford. No part of either questionnaire may be reproduced without the prior written consent of Oxford University Innovation Limited.

Oxford University Innovation Limited, Buxton Court, 3 West Way, Oxford OX2 0JB.  
<http://innovation.ox.ac.uk/outcome-measures/parkinsons-disease-questionnaire-pdq-39-pdq-8/>

The PDQ-39 and PDQ-8 were written by Crispin Jenkinson, Ray Fitzpatrick and Viv Peto who have asserted their moral rights in both instruments.

PDQ-Carer © 2011 Oxford University Innovation Limited.  
No part of either questionnaire may be reproduced without prior written consent.  
Contact Clinical Outcomes at Oxford University Innovation Limited.  
Oxford University Innovation Limited, Buxton Court, 3 West Way, Oxford OX2 0JB.

The PDQ-Carer questionnaire was written by Crispin Jenkinson, Sarah Dummett, Ray Fitzpatrick, Jill Dawson, Michele Peters and Laura Kelly who have asserted their moral rights in it.

Health Services Research Unit  
University of Oxford  
Department of Public Health  
Old Road Campus  
Oxford, OX3 7LF, UK  
[www.publichealth.ox.ac.uk/units/hsru](http://www.publichealth.ox.ac.uk/units/hsru)

## SUMMARY

This report is intended as a reference manual for the Parkinson's Disease Questionnaire 'long form' (the PDQ-39), short form (the PDQ-8) and the Parkinson's Disease Carer Questionnaire (PDQ-Carer). All three scales are self completion instruments designed to address aspects of functioning and well-being adversely affected by Parkinson's disease.

The main points covered in this report are:

- an outline of the epidemiology of Parkinson's Disease;
- a brief description of the symptoms most commonly associated with Parkinson's disease;
- a review of the development of the 39 item Parkinson's Disease Questionnaire;
- a comparison of results from the PDQ-39 with other subjective health and clinical outcome measures;
- an assessment of the sensitivity to change of the PDQ-39;
- documentation of the derivation of a summary index of health status from the PDQ-39;
- information concerning the derivation of an eight item measure of health status, the PDQ-8, from the PDQ-39 which can provide, with little loss of information, the PDQ summary index;
- an example of cross cultural validation of the PDQ-39;
- an example of a method of imputing missing data in clinical trials;
- a review of the development of the Parkinson's Disease Carer Questionnaire (PDQ-Carer), which assesses the impact of PD on informal carers;
- a copy of the PDQ-39;
- a copy of the PDQ-8;
- a copy of the PDQ-Carer
- a copy of the scoring systems for the PDQ-39, PDQ-8, PDQ-SI and PDQ-Carer.

## THE AUTHORS

**Crispin Jenkinson, BA (London), MSc, DPhil (Oxford)**

Professor of Health Services Research in the Department of Public Health, University of Oxford, and fellow of Harris Manchester College.

**Ray Fitzpatrick, MA (Oxford), MSc, PhD (London), FMedSci**

Professor of Public Health and Primary Care in the Department of Public Health, University of Oxford, and fellow of Nuffield College.

**Viv Peto, BA (Oxford)**

Research Officer in the Department of Public Health, University of Oxford.

**Sarah Dummett**

Research Officer at the Health Services Research Unit, Department of Public Health, University of Oxford.

**David Morley, BSc (Buckingham), MSc, PhD (London)**

Research Officer at the Health Services Research Unit, Department of Public Health, University of Oxford.

**Phil Saunders**

Head of Information Technology at the Health Services Research Unit, Department of Public Health, University of Oxford.

## **ACKNOWLEDGEMENTS**

We wish to thank Parkinson's UK (formerly the Parkinson's Disease Society) and its members and local branches who have participated in much of the development work outlined in this manual.

Development of the PDQ-Carer was funded by The European Federation of Neurological Associations (EFNA).

We are particularly grateful for the ongoing support and assistance of Mary Baker MBE, President, European Brain Council; former Chief Executive, Parkinson's Disease Society; and past president, EFNA. Her vision and support have played an important role in outcomes measurement in Parkinson's disease. Our thanks also go to Amanda Worpole, President EFNA, for her support with this manual as well as current research initiatives at the Health Services Research Unit in Oxford.

# CONTENTS

I. Overview .....	7
II. Parkinsons Disease: Epidemiology, Symptoms and Treatment .....	9
III. Development of the PDQ-39.....	20
IV. Comparison Of The PDQ-39 with a Generic Measure Of Health Status and Clinical Assessments .....	30
V. Sensitivity to Change of the PDQ-39.....	36
VI. The PDQ-39 Summary Index and the PDQ-8 Summary Index .....	40
VII. Cross Cultural Analysis of the PDQ-39: Results from America, Canada, Japan, Italy and Spain .....	47
VIII. Cross Cultural Evaluation of the Short Form 8 Item Questionnaire (PDQ-8): Results from America, Canada, Japan, Italy and Spain .....	54
IX. Using THE PDQ-39 and Pharmaceutical Industry Compliance .....	61
X. Evidence for a Method of Imputing Missing Data for the PDQ-39 .....	63
XI. The Parkinson's Disease Carer Questionnaire (PDQ-Carer): Development and Validation .....	72
XII. Concluding Remarks .....	80
Appendices .....	81
1. The Parkinson's Disease Questionnaire (PDQ-39) .....	82
2. The Short Form Parkinson's Disease Questionnaire (PDQ-8) .....	88
3. The Parkinson's Disease Carer Questionnaire (PDQ-Carer) .....	90
4. Coding for the PDQ-39, PDQ-8 and PDQ-Carer .....	95
5. Administration Procedures.....	99
6. PDQ Publications .....	101
7. List of PDQ-39 Translated Versions .....	105
References .....	108
Index.....	129