

The Care of Late Stage Parkinsonism Consortium

University College London



London, UNITED KINGDOM

**Stichting Katholieke
Universiteit**



**Nijmegen, THE
NETHERLANDS**

**Instituto de Medicina
Molecular**



Lisbon, PORTUGAL

**Klinikum der Universität
München**



München, GERMANY

Lunds Universitet



Lund, SWEDEN

**Philipps-Universität
Marburg**



Marburg, GERMANY

**Centre Hospitalier
Universitaire de Bordeaux**



Bordeaux, FRANCE

The CLASP project takes place at the following European centres:

- University Hospital Bordeaux, France (Bordeaux)
- Philipps-University Marburg, Germany (Marburg)
- Klinikum der Universität München, Germany (Munich)
- Stichting Katholieke Universiteit, Nijmegen, The Netherlands (RUMC)
- Instituto de Medicina Molecular, Portugal (Lisbon)
- Lund University, Sweden (Lund)
- University College London, United Kingdom (UCL)

About

The CLASP study evaluates the well-being and quality of life for patients in the later stages of Parkinsonism, and assesses the needs of carers. Our project compares the effectiveness of different health and social care systems in six different European countries in order to lay the foundation for improved outcomes in this population.

Our cross-sectional study assesses patients, carers and health care providers through questionnaires and interviews. The interventional arm of our study investigates how patients benefit from management advice and guidance by a movement disorders specialist, as compared to their usual care arrangements.

Evaluation of our trial will serve as a basis for recommendations in the management of advanced Parkinsonism. As part of the project we also carry out a systematic literature review of care systems and procedures. We interrogate national and regional databases to describe current care practices, healthcare resources, drug interventions, and other predictors of better outcome. We also evaluate potentially useful outcome measures for use in this patient group.

- [Project summary page - pdf](#)

We are grateful for the help received on our project from patient and carer groups. Amongst many contributors, we received feedback from the European Parkinson's Disease Association, and the Research Steering Group of service users at the Royal Free Hospital, London.

If you have any feedback, please contact the project team at clasp@ucl.ac.uk.

The Project

The aim of this project is to evaluate the needs and provision of care for patients in the late stages of Parkinsonism and their carers in several European countries, to compare the effectiveness of different health and social care systems, and to lay the foundation for improved outcomes in this population. We will undertake an in-depth assessment of patients and their care arrangements in a population recruited through networks in six European countries. The systems and procedures that are used in the provision of care will be reviewed through a systematic literature review, interviews and assessments of patients, carers and health care providers, and through a trial comparing assessment by a specialist with management suggestions, guidance and access to telephone advice to that of usual care.

Through interviews, questionnaire assessment and review of current health-care and social care arrangement, we will assess the needs, provision of care and use of health-care resources, and their impact on patient and carer outcomes in different countries. National and regional databases will also be interrogated to identify current practice and use of healthcare resources and drug usage. A systematic literature review of the evidence for effective management strategies, analysis of the study data, and evaluation of change in outcomes following specialist review will provide the basis for recommendations in the management of late stage Parkinsonism. We will also evaluate potentially useful outcome measures for use in this patient group.

In addition to charting the needs and current care provision for late stage Parkinsonism in different European countries, its cost and effectiveness, and an analysis of health-care and social care predictors of improved outcome, the project will produce a platform for the

assessment of patients with late stage Parkinsonism, their current treatment and care provision, as well as guidelines on the management of this late disease phase.

Participating Centres

This European consortium offers collaboration of several established research centres and will be coordinated by the UK partner.

MAJOR PARTICIPANTS

1. University College London, UK
2. University of Marburg, Germany
3. University of Lisbon, Portugal
4. University of Nijmegen, The Netherlands
5. University of Lund, Sweden
6. University Hospital Bordeaux, France
7. University of Munich, Germany

The configuration and members of this consortium ensure that an adequate number of patients with late stage Parkinsonism are included in the study, covering several areas with the EU with different health-care systems. These differences provide the opportunity to assess the comparative effectiveness of different systems. The members have been chosen on the basis of their expertise and experience in undertaking large cohort studies as well their expertise in Parkinson's diagnosis, management and research. The consortium also has expertise in health economic evaluations and outcomes measures research as well as palliative care.

The CLASP team

Members of the group are experienced in undertaking large cohort studies and have considerable expertise in Parkinson's diagnosis, management, and palliative care. The consortium also has expertise in quantitative and qualitative research, evaluation of economics and health outcomes measures.

The multinational nature of the group allows covering several areas with the European Union. This provides an opportunity to assess the comparative effectiveness of different health-care systems.

Primary research sites:

- University College London, United Kingdom (UCL)
- Stichting Katholieke Universiteit, Nijmegen, The Netherlands (RUMC)
- Lund University, Sweden (Lund)
- Philipps-University Marburg, Germany (Marburg)
- Instituto de Medicina Molecular, Portugal (Lisbon)
- Klinikum der Universität München, Germany (Munich)

- University Hospital Bordeaux, France (Bordeaux)

For details of the individual centres, please follow the links or visit our Contact us page.

Alternatively, contact the coordinating team: clasp@ucl.ac.uk.

Care of Late Stage Parkinsonism (CLaSP) Study

The CLaSP study is a European research study being carried out in 6 different countries looking into the health needs and care received by those with advanced stage Parkinson's, or Parkinsonism, and their carers. The project aims to improve the care of future patients in this later stage of the condition

What has the study involved?

The study has involved a review of physical movements as well as asking some questions about health, needs, memory, circumstances and health care provision, along with previous treatments.

The study is no longer recruiting new participants but is now completing the follow-up assessments of those already enrolled in the study.

FAQs

Will this help me?

While you may not directly benefit from this study you will be making a valuable contribution to improving the future care of those with Parkinson's and their carers.

What if I no longer want to take part?

You are free to withdraw at any time. Your decision to take part or not will not affect the care you are receiving.

If I take part, will my information be kept confidential?

Any information collected during the study will be kept confidential. Assessment and test results will be stored on a secure, confidential, computer network on the University College London (UCL) system, accessible only to members of the research team.

How do the changes in data protection law affect the information I have given you?

Under the General Data Protection Regulation, UCL is the sponsor for this study based in the United Kingdom. We will be using information from medical records in order to undertake this study and will act as the data controller for this study. This means we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Who do I contact for further information?

Please call, text or email the research teams in your country of residence by clicking on these links below

- France (Bordeaux)
- Germany (Marburg)
- Germany (München)
- Netherlands (Nijmegen)
- Portugal (Lisbon)
- Sweden (Lund)
- United Kingdom (London)

Care of Late Stage Parkinsonism is a multicentre study carried out in 6 European countries. In the UK, we have been working together with the National Health Service, care homes, and patient organizations.

The study is funded through the [EU Joint Programme - Neurodegenerative Diseases Research \(JPND\)](#) initiative.

Reason for the study

The aim of this study is to determine the needs of those patients in the late stages of parkinsonism and their carers, how they are currently met in different European countries, and how their care could be improved. We suspect that there are number of unmet needs and that these can be addressed better. We therefore assess the problems and needs of patients with late stage parkinsonism and their carers through examination and questions, and interrogate existing health care databases. We also study the effect of a specialist assessment with treatment recommendations compared to those who receive their normal care.

Research question

What is the impact of late stage Parkinsonism on patients and their carers and families and what are their medical and social needs, costs and use of health-care resources?

How appropriate and valid are the existing assessment tools in this population?

How do disability and disease severity milestones (psychosis, dementia, falls, wheelchair-bound, institutionalisation) progress over time in these patients?

What are the health-care and social determinants of outcome once disease variables are accounted for?

What is the impact of different health-care pathways?

What are management strategies that have been shown to be effective in late stage Parkinsonism?

What is the impact of a specialist review with management recommendations, provision of guidance and access to telephone assistance?

The Research Study

This is a longitudinal, multicentre, observational cohort study in six European countries with different health-care and social care models. It uses clinical assessments, questionnaires and interviews with patients, carers and health care staff, and interrogation of existing databases.

Study Participants

(1) Patients who have late-stage Parkinsonism classified according to Hoehn and Yahr stage (HY) IV or V in the “On”-state or have developed significant disability (Schwab and England stage 50% or less) in “On”, and (2) their informal carers.

Inclusion Criteria: Late stage Parkinsonism will be defined as patients who are in Hoehn and Yahr stages IV or V during On, or have developed significant disability (Schwab and England stage 50% or less) in “On” and have a disease duration of at least 7 years.

Exclusion criteria: We will exclude patients with PD in Hoehn and Yahr stages I-III., and patients with symptomatic Parkinsonism such as normal pressure hydrocephalus or drug-induced Parkinsonism (onset following treatment with drugs known to cause Parkinsonism), except if persisting following discontinuation of the causative drug. We will exclude patients with Parkinsonism with a clear history of dementia occurring before the onset of Parkinsonism as care pathways for this patient group may differ from that of patients initially presenting with motor problems. In addition, the occurrence of Parkinsonism in the context of advanced dementia is likely to be recorded unreliably.

Care homes have been invited to contribute to the interview if they would like to. Current management arrangements have been explored, as well as knowledge of the needs and experiences of caring for people with Parkinsonism from the perspective of the patient, carers and health care professionals. We hope to learn more about the difficulties of both providing and accessing care for people with Parkinsonism and how this can be improved.

Governance

The study has been approved by NRES Committee London – Camden and Islington Research Ethics committee.

Contact details

Please [contact the CLASP study team](#) in the country of your residence for more information by following this link.

For general enquiries, please contact: clasp@ucl.ac.uk

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KONTAKT
Wenn Sie in Bayern wohnen, sind Sie herzlich eingeladen an einer der Versammlungstermine teilzunehmen. Wenn Sie sich Hilfe bei der Übersetzung wünschen (Tel.: 089400 17142) oder Bestätigung wünschen.

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News

The study has now completed both recruitment and analysis, having recruited 692 participants from across 6 countries, 123 of whom were from the UK. The findings from the study can be viewed in the publications that are available below. The findings suggest areas that could be improved upon in current treatments, particularly ways in improving quality of life for example regular access to seeing a Parkinson's nurse and other specialists within the multidisciplinary team. The papers also identify the particular symptoms or situations that healthcare professionals should be aware of as signs of significant deterioration. Findings also explore the burden on those spouses and family-members who care for those with Parkinson's .

- Balzer-Geldsetzer et al. [Study protocol: Care of Late-Stage Parkinsonism \(CLaSP\): a longitudinal cohort study](#). BMC Neurology (2018) 18:185
- Hommel et al. [Optimizing Treatment in Undertreated Late-Stage Parkinsonism: A Pragmatic Randomized Trial](#). Journal of Parkinson's Disease, vol. 10, no. 3, pp. 1171-1184, 2020.
- Hommel et al. [The Prevalence and Determinants of Neuropsychiatric Symptoms in Late-Stage Parkinsonism](#). MOVEMENT DISORDERS CLINICAL PRACTICE 2020; 7(5): 531–542.
- Hosking et al. [Characteristics of Patients with Late-Stage Parkinsonism Who are Nursing Home Residents Compared with those Living at Home](#). Journal of the American Medical Directors Association, Volume 22, Issue 2, 2021, Pages 440-445.e2
- Kalampokini et al. [Caregiver Burden in Late-Stage Parkinsonism and Its Associations](#). Journal of Geriatric Psychiatry and Neurology. October 2020.

- Read J, et al. [Experiences of health services and unmet care needs of people with late-stage Parkinson's in England: A qualitative study](#). PLoS ONE 14(12) 2019
- Rosqvist et al. [Perspectives on Care for Late-Stage Parkinson's Disease](#). *Parkinson's Disease*, vol. 2021, Article ID 9475026, 11 pages, 2021.
- Rosqvist et al [Factors Associated with Health-Related Quality of Life in Late-Stage Parkinson's Disease](#). MOVEMENT DISORDERS CLINICAL PRACTICE 2021; 8(4): 563–570
- Schrag et al. [The late stage of Parkinson's –results of a large multinational study on motor and non-motor complications](#). *Parkinsonism & Related Disorders*, June 2020.