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**Sponsor: University College London (UCL)**

**Project title**: Care of Late Stage Parkinson’s (CLaSP)

The following files have been archived:

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| File name | File description  |
|  | **All are Excel files containing longitudinal quantitative data from UK cohort of CLaSP study. Each file will contain data for a max of 148 participants, for up to 4 visits.** |
| CGI carer.xlsx | Clinical Global Impressions scale rating/judgement outcome measure |
| CGI clinician.xlsx |
| CGI patient.xlsx |
| charlsonindex.xlsx | Charlson Index to measure comorbidities (Charlson 1994) |
| clockdrawing.xlsx | Clock drawing cognitive test (Folstein 1975) |
| comorbidities.xlsx | Participants’ comorbidities by participant (free text) |
| DEMQOL-Proxy.xlsx | Patient Quality of Life – completed by proxy in cases where participant with Parkinson’s is cognitively unable to do so (Institute of Psychiatry, King's College London) |
| eq5D3lCarer.xlsx | ED-5D-3L measuring Carer health status (EuroQolGroup 1990) |
| eq5D3lPatient.xlsx | ED-5D-3L measuring Patient health status (EuroQolGroup 1990) |
| esas\_pd.xlsx | Edmonton Symptom Assessment system measuring basic palliative assessment (Miyasaki 2012) |
| GDS.xlsx | Geriatric Depression Scale (Yesevage 1983) |
| ICB\_DDS.xlsx | Dopamine Disreg |
| lastAssessment.xlsx | When last seen by specialist |
| lexicalfluency.xlsx | Verbal fluency cognitive test |
| likertscale\_carer.xlsx | Satisfaction with Support scale – carer completed |
| likertscale\_patient.xlsx | Satisfaction with Care scale– patient completed |
| MMSE.xlsx |  Mini Mental State Examination (Folstein 1975) |
| NMS\_Scale.xlsx | Non-motor symptom scale (Chaudhuri 2007) |
| nph.nh\_a.xlsx | Twelve domains of Neuropsychiatric Inventory (NPI-12) (Cummings 1994) |
| nph.nh\_b.xlsx |
| nph.nh\_c.xlsx |
| nph.nh\_d.xlsx |
| nph.nh\_e.xlsx |
| nph.nh\_f.xlsx |
| nph.nh\_g.xlsx |
| nph.nh\_h.xlsx |
| nph.nh\_i.xlsx |
| nph.nh\_j.xlsx |
| nph.nh\_k.xlsx |
| nph.nh\_l.xlsx |
| pdq8.xlsx | Quality of life and health status (Peto 1998) |
| pill\_questionnaire.xlsx | Pill questionnaire (Dubois 2007) |
| rec\_fol\_all.xlsx | *Intervention activity* |
| reco\_intervent.xlsx |
| resourceutil\_1.xlsx | Resource data including course of illness resource use, patient and carer work situations |
| resourceutil\_1\_grp xlsx |
| resourceutil\_2.xlsx |
| resourceutil\_3.xlsx |
| resourceutil\_4.xlsx |
| script\_tel\_q.xlsx | Barriers to intervention |
| smile. xlsx | SMiLE measure for meaning in life (Fegg 2008) |
| updrs1.xlsx | Unified Parkinson's Disease Rating Scale (UPDRS) (Fahn 1987 Schwab 1969)  |
| Updrs2.xlsx |
| Updrs3.xlsx |
| Updrs4.xlsx |
| Updrs5.xlsx |
| Updrs6.xlsx |
| visit\_medicat.xlsx | Participants medications |
| Zaritburden. .xlsx | Zarit burden measure for carer burden (Zarit 1980) |

**Publications** based on this data:

[Schrag, A.](https://rps.ucl.ac.uk/userprofile.html?uid=5068); Hommel, A. L. A. J.; Lorenzl, S.; Meissner, W. G.; Odin, P.; Coelho, M.; Bloem, B. R.; Dodel, R.; Ferreira, J.; Fabbri, M.; Tison, F.; Foubert-Samier, A.; Read, J.; Meinders, M.; Koopmans, R.; Richinger, C.; Rosqvist, K.; Wittenberg, M.; Neuser, P. (2020) The late stage of Parkinson's –results of a large multinational study on motor and non-motor complications. Parkinsonism and Related Disorders. 10.1016/j.parkreldis.2020.05.016

Adrianus L.A.J. Hommela, Marjan J. Meindersb, Nico J. Weerkampm, Carmen Richingerg,

Christian Schmotzg, Stefan Lorenzlg, Richard Dodelh, Miguel Coelhoj, Joaquim J. Ferreiraj,

Francois Tisone, Thomas Boraude, Wassilios G. Meissnere*,*f , Kristina Rosqvisti, Jonathan Timpkai,Per Odini, Michael Wittenbergk, Bas R. Bloeml, Raymond T. Koopmansd and Anette Schrag*,*∗and the CLaSP consortium.Optimizing Treatment in Undertreated Late-Stage Parkinsonism: A Pragmatic Randomized Trial. Journal of Parkinson’s Disease 10 (2020) 1171–1184 DOI 10.3233/JPD-202033. IOS Press

Adrianus L.A.J. Hommel, MD, MSc,1,2 Marjan J. Meinders, PhD,3 Stefan Lorenzl, MD, PhD,4,5 Richard Dodel, MD, PhD,6 Miguel Coelho, MD, PhD,7,8,9 Joaquim J. Ferreira, MD, PhD,7 Brice Laurens, MD, PhD,10,11 Umberto Spampinato, MD, PhD,10,11Wassilios Meissner, MD, PhD,10,11,12,13 Kristina Rosqvist, PhD,14 Jonathan Timpka, MD,14 Per Odin, MD, PhD,14 Michael Wittenberg, PhD,Bas R. Bloem PhD,1 Raymond T. Koopmans, MD, PhD,16,17 and Anette Schrag, MD, PhD,18, the Care of Late-Stage Parkinsonism Consortium.The Prevalence and Determinants of Neuropsychiatric Symptoms in Late-Stage Parkinsonism. MOVEMENT DISORDERS CLINICAL PRACTICE 2020; 7(5): 531–542. doi: 10.1002/mdc3.12968

Kalampokini S, Hommel ALAJ, Lorenzl S, Ferreira JJ, Meissner WG, Odin P, Bloem BR, Dodel R, Schrag AE. [Caregiver Burden in Late-Stage Parkinsonism and Its Associations.](https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fpubmed.ncbi.nlm.nih.gov%2F33094677%2F&data=04%7C01%7C%7C54d74cd2e4714644195208d8c77bedd3%7C1faf88fea9984c5b93c9210a11d9a5c2%7C0%7C0%7C637478682362452224%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C1000&sdata=lNq63fYY9v0IxoCviq%2FMjMG19whqCGEn%2FI1ejWlDblM%3D&reserved=0) J Geriatr Psychiatry Neurol. 2020 Oct 23:891988720968263

Hosking A, Hommel AALJ, Lorenzl S, Coelho M, Ferreira JJ, Meissner WG, Odin P, Bloem BR, Dodel R, Schrag A; Care of Late Stage Parkinsonism (CLaSP) Consortium**.** Characteristics of Patients with Late-Stage Parkinsonism Who are Nursing Home Residents Compared with those Living at Home. J Am Med Dir Assoc. Jul 25 2020 .22(2):440-445.e2
DOI: [10.1016/j.jamda.2020.06.025](https://doi.org/10.1016/j.jamda.2020.06.025) PMID: 32723531

Schrag A, Hommel ALAJ, Lorenzl S, Meissner WG, Odin P, Coelho M, Bloem BR, Dodel R; CLaSP consortium. [The late stage of Parkinson's -results of a large multinational study on motor and non-motor complications.](https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fpubmed.ncbi.nlm.nih.gov%2F32505085%2F%3Ffrom_term%3Dschrag%2Ba%26from_sort%3Ddate%26from_pos%3D1&data=04%7C01%7C%7C54d74cd2e4714644195208d8c77bedd3%7C1faf88fea9984c5b93c9210a11d9a5c2%7C0%7C0%7C637478682362462216%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C1000&sdata=FjxbmopiOMt9IMFcmJB%2BgKLmDH4jlfxEaNBB2qN2i3U%3D&reserved=0) Parkinsonism Relat Disord. 2020 May 21;75:91-96.