**Summary of data that can be useful for the attachment**

**PwMND**

MQOL – R (primary outcome)

HADS

ALS-FRS-Revised (severity of MND)

* Minimal to moderate group (als\_score0 >39)
* mild to moderate severity (als\_score0 >29 & als\_score0 <40)

Kings Stage ( I calculated this from ALS-FRS score)

EQ-5D-5L

EQ-VAS

Acceptance and Action Questionnaire (an indication of worries, being afraid etc)

3. Rate of deterioration

Variable prebase\_det\_tert

\*\* Lowest deterioration n = 64 medium deterioration n = 64 and highest deterioration n = 63

Resource use – in a separate dataset but I can prepare another dataset with everything.

Demographics

**Caregivers**

EQ-5D-5L [baseline (n = 85), 6 months (n = 70), 9 months (n = 67) ]

EQ-VAS [baseline (n = 86), 6 months (n = 70), 9 months (n = 67) ]

Zarit Burden Interview (caregiver) - 22 questions [baseline (n = 86), 6 months (n = 69), 9 months (n = 66)]

carer\_ethnicity carer\_relationship carer\_education\_lvl carer\_occupation\_stat carer\_paid\_work\_ft\_pt carer\_occupation\_lvl carer\_occ\_l caring\_duration caring\_average calc\_age\_c (Those questions were asked at baseline and the precise questions can be found in the file by looking in the identifier column in the fields tab (Filename: COMMEND Database specification located at X:\HAR\_WG\WG\WELLCOME\_COMMEND\Data).