FILE NOTES: MODEM baseline and follow-up data

**Format:** The datasets are in STATA version 14 format.

**Unique identifier(s):** ParticipantID

**Derived variables:** For all health and well-being measures summary scores have been calculated and included in the dataset. Summary score algorithms are publicly available and can be accessed online.

**Changes from baseline:** A change was made in the content of the Client Services Resource Inventory (CSRI) questionnaire during data collection at follow-up. That is, some sample dyads completed their follow-up visit prior to the change in questionnaire. Both versions of the CSRI questionnaire are available on the Data Archive. The data file contains additional variables to ensure that the variables incorporate data from both versions of the questionnaire.

N=26 dyads completed the follow-up interview prior to the change in CSRI (and therefore completed the “CSRI v1 (baseline version)” and have the same carer as baseline.

N=5 dyads completed the follow-up interview prior to the change in CSRI (and therefore completed the “CSRI v1 (baseline version)” but their carer was different from baseline. These people completed the “CSRI v1 (baseline version)”, to ensure we capture their full demographic data. The variable ‘carer\_same’ identifies the ‘new’ carers. The demographic data for new carers is denoted by the variables with the suffix ‘\_c2’ in the dataset.

N=64 dyads completed the baseline interview but did not complete the follow-up interview (e.g. refused, deceased).

N=212 dyads completed the follow-up interview after the change in CSRI. They completed the “CSRI v2 (revised version)”. The demographic information for these dyads can be obtained from the MODEM baseline data (i.e., merging the baseline and follow-up data by ParticipantID).

A variable ‘flag’ has been added to the data which indicates which version of the CSRI was used in the interview at the follow-up interview. A value of 1 indicates that the original, baseline version was used; a value of 2 indicates that the revised version was used.

**Data cleaning:** For follow-up data double entry checks were carried out on the data to ensure that there were no errors. Each month each Research Assistant (RA) double entered a sample of another RA’s dataset. As a result, we have double entered 40+ participants’ datasets. Double entry checks revealed very minor discrepancies in entry (typically 1-2%), which were usually attributable to variation in plain text entry.