Appendix 2: Data extraction templates

DEMQOL Data Extraction Form - Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *
   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *
   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- ◯ RCT
- ◯ Controlled Trial
- ◯ Pre-Post
- ◯ Cohort
- ◯ Case-control
- ◯ Cross-sectional
- ◯ Qualitative
- ◯ Mixed
- ◯ Others

10. If Mixed design, provide description

Mark only one oval.

- ◯ Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- ◯ Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- ◯ Concurrent- both quantitative and qualitative methods are conducted in parallel

11. If others, provide description

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Sample

State the sample size, and separately for each arm of the study (e.g., control, treatment1, treatment2), if applicable

14. Sample size *

How many people were asked to participate.

_____

_____

_____

_____

_____

15. Sample size

How many people actually participated and provided data.

16. Age (Age range, Mean age) *

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article.

17. Gender/Sex *

Extract the percentage of the sample that was female/women and/or male/men

Settings (Check all that apply)

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities).

18. Site (check all that apply) *

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

19. Number of Sites *

Were the number of sites specified?

Mark only one oval.

- ( ) Yes
- ( ) No

20. Number of Sites *

For those who agreed to participate in the study.

_____

21. Number of Sites *

For those who were included in the data analysis.

_____

Cognitive Impairment	This involves: name of the tool used to measure cognitive health status, level of cognitive health status

22. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

23. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

24. Percentage of participants described as having mild, moderate or severe cognitive impairment *

25. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version Used

26. DEMQOL Instruments Version(s) used *

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

27. DEMQOL Language *

Study Outcomes

28. Additional Study Variables Assessed Other Than The DEMQOL *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: GDS- Depression

Psychometric properties of the instrument

How DEMQOL was used by the authors in the study. It may have been used in more than one way.

29. Reliability (Internal consistency) *

Assesses how tool items are inter-correlated (usually reporting Cronbach's alpha). Report reliability in the form of numerical value given for internal consistency. If not reported, please respond as 'not reported'.

30. Reliability (Test-retest) *

Assesses correlation of scores measured by the same person at different times (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for test- retest. If not reported, please respond as 'not reported'.

31. Reliability (Inter-rater) *

Assesses correlation of scores measured by two or more independent raters at the same time (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for inter-rater. If not reported, please respond as 'not reported'.

32. Reliability (Inter-method) *

Assesses correlation of scores obtained by different assessment methods (e.g observations vs self-report or self-report vs proxy). Usually as Kappa, intra-cross correlation, or similar correlation coefficients. Report reliability in the form of numerical value given for inter-method. If not reported, please respond as 'not reported'.

33. Validity (Content validity) *

Assessed by ratings given by content experts (usually researchers or clinicians). Ratings may either be qualitative, or quantitative using standardized scales to assess relevance and comprehensibility of each item based on content experts perceptions. Report numerical value given for content validity. If not reported, please respond as 'not reported'.

34. Validity (Response Process validity) *

Summarize the findings related to how well target persons understood the questionnaire. If not reported, please respond as 'not reported'.

35. Validity (Factorial or Internal Structure Validity) *

Report whether exploratory or confirmatory factor analyses were conducted, report the number of factors found and model fit indices (if reported). If not reported, please respond as 'not reported'.

36. Validity (Relationship with other variables) *

Statistical modelling is used to test pre-specified hypotheses. To be specific, models assess whether known predictors of QOL are associated with QOL as measured by the DEMQOL as expected. Or models assess whether QOL as measured by the DEMQOL are associated with known consequences of poor QOL such as reduced social engagement and depression. Report the numerical value(s) given for the relationship with other variables. If not reported, please respond as 'not reported'.

37. Feasibility or Acceptability *

Must be reported in the results section because it needs to be scientifically assessed. If not reported, please respond as 'not reported'.

DEMQOL Data Extraction Form - non-Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *

   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *

   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- ◯ RCT *Skip to question 12*
- ◯ Controlled Trial *Skip to question 12*
- ◯ Pre-Post *Skip to question 12*
- ◯ Cohort *Skip to question 12*
- ◯ Case-control *Skip to question 12*
- ◯ Cross-sectional *Skip to question 12*
- ◯ Qualitative *Skip to question 12*
- ◯ Mixed *Skip to question 10*
- ◯ Others *Skip to question 11*

Specify mixed

10. If Mixed design, provide description *

Mark only one oval.

- ◯ Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- ◯ Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- ◯ Concurrent- both quantitative and qualitative methods are conducted in parallel

Skip to question 12

Specify other

11. If others, provide description *

Methods of data collection

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Settings

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities). Check all that apply.

14. Setting(s) *

Check all that apply

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

15. Number of sites approached *

For each setting specified above, enter the number of sites that were asked to participate. For example, if researchers approached 12 nursing homes and 11 assisted living facilities, enter: NHs: 12; AL: 11. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

16. Number of sites agreed to participate *

For each setting specified above, enter the number of sites that agreed to participate. For example, if 10 nursing homes and 8 assisted living facilities agreed to participate, enter: NHs: 10; AL: 8. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

17. Number of sites included in data analyses *

For each setting specified above, enter the number of sites that were included in the data analyses. For example, if 8 nursing homes and 7 assisted living facilities were included in the data analyses, enter: NHs: 8; AL: 7. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

Sample

Refers to the recruited individuals (e.g., patients, residents, family/friend caregivers, care aides, nurses, ...)

18. Number of persons approached *

For each participant group, enter the number of persons that were asked to participate. For example, if researchers approached 200 nursing home residents and 48 care aides, enter: NH residents: 200; care aides: 48. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

19. Number of persons agreed to participate *

For each participant group, enter the number of persons that agreed to participate. For example, if 150 nursing home residents and 24 care aides agreed to participate, enter: NH residents: 150; care aides: 24. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

20. Number of persons included in data analyses *

For each participant group, enter the number of persons that were included in the data analyses. For example, if 140 nursing home residents and 20 care aides were included in the analyses, enter: NH residents: 140; care aides: 20. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

21. Age

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

22. Sex

Extract the percentage of the sample that was female/women and/or male/men. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

Cognitive Impairment

This involves: name of the tool used to measure cognitive health status, level of cognitive health status

23. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

24. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

25. Percentage of participants described as having mild, moderate or severe cognitive impairment *

26. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version

27. DEMQOL Instruments Version(s) used *

Check all that apply

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

28. DEMQOL Language

_____

Use of DEMQOL

29. How was the DEMQOL used in this study

Check all that apply

Tick all that apply.

☐ As a dependent variable - i.e. study assessing factors associated with QoL or how QoL differs between groups

☐ As an independent variable or study covariate - i.e. study assessed how QoL influences other study outcomes

Other Dependent Variables

Don't list the DEMQOL here. Only list dependent variables other than DEMQOL scores.

30. Dependent variables (other than DEMQOL) *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no dependent variables other than the DEMQOL were included, enter: NA.

_____

_____

_____

_____

_____

Other Study Variables

Don't list the DEMQOL here. Only list independent variables and model covariates other than DEMQOL scores.

31. Independent variables (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes ARE reported (e.g. regression coefficients, correlations, etc.) Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no independent variables were included, enter: NA.

32. Modelling covariates (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes are NOT reported. Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no model covariates were included, enter: NA.

Main Findings

33. Main findings of the study