

CODE BOOK - CAREGIVER
FOLLOW-UP MEASUREMENT - TX

TOPICS-MDS

'The Older Persons and Informal Caregivers Survey Minimum Data Set'

TOPICS-MDS





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This is the codebook for the follow-up TOPICS-MDS data and it explains the coding used in the database.

Baseline and Follow-up measurements

The variable names indicate whether a variable belongs to a baseline (T0) or a follow-up measurement (Tx):

T0	Baseline assessment
T3	Follow-up measurements after 3 months
T4	Follow-up measurements after 4 months
T6	Follow-up measurements after 6 months
T8	Follow-up measurements after 8 months
T12	Follow-up measurements after 12 months
T16	Follow-up measurements after 16 months
T18	Follow-up measurements after 18 months
T21	Follow-up measurements after 18 months
T24	Follow-up measurements after 24 months
T32	Follow-up measurements after 32 months
T36	Follow-up measurements after 36 months

Note: T3, T4, T8, T16, T18, T21, T24, T32 and T36 are only available for a few studies



General data

ProjectID	TOPICS-MDS study number
PersonIDCG	TOPICS-MDS individual ID of caregiver
TX_cg_ses2006	Social economic status score 2006 of the caregiver
TX_cg_ses2010	Social economic status score 2010 of the caregiver
TX_cg_corop	Corop code of the caregiver
TX_cg_sted	Urbanization degree of the caregiver
TX_cg_prov	Province of the caregiver
TX_cg_ses2006cr*	Social economic status score 2006 of the care receiver
TX_cg_ses2010cr*	Social economic status score 2010 of the care receiver
TX_cg_coropcr*	Corop code of the care receiver
TX_cg_stedcr*	Urbanization degree of the care receiver
TX_cg_provcr*	Province of the care receiver
<i>Please see Appendix 1 for more information on the coding</i>	
TX_cg_aafndat	date on which the caregiver filled out the questionnaire dd/mm/yyyy
<i>Three additional variables were created:</i>	
TX_cg_aafnday	Day on which the caregiver filled out the questionnaire
TX_cg_aafnmo	Month on which the caregiver filled out the questionnaire
TX_cg_aafnyr	Year on which the caregiver filled out the questionnaire
TX_cg_aques	Questionnaire is completed by using:
	1= A face-to-face interview
	2= A telephone interview
	3= A written/mailed questionnaire/ a web-based questionnaire (internet)
	4= A mailed questionnaire that was checked afterwards in a personal interview
	5= A mailed questionnaire that was checked afterwards in a telephone interview
TX_cg_agecr*	Baseline age of care receiver on the date of filling out the questionnaire by caregiver
TX_cg_asexcr*	Sex of the care receiver
	0= Male
	1= Female
TX_cg_age	Baseline age of caregiver on the date of filling out the questionnaire
TX_cg_asexecg	Sex of the caregiver
	0 = Male
	1= Female

** will not be provided if both care receiver and caregiver data are requested*



TX_cg_arelatt What is your relationship with the *care receiver*? I am..

1= Husband/ wife/ life partner

2= Sister/ brother/ brother-in-law/ sister-in-law

3= Daughter (in law)/ son (in law)

4= Other, namely

TX_cg_arelattoth Other relationship with *care receiver*, namely...

TX_cg_atogether Do you live together with the *care receiver*?

0= Yes

1= No



Health

The following questions are about your health. Please tick the answer that best fits your situation.

(http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html)

TX_cg_health1 In general, would you say your health is:

- 1= Excellent
- 2= Very good
- 3= Good
- 4= Fair
- 5= Poor

TX_cg_health2 Compared to one year ago, how would you rate your health in general now?

- 1= Much better now than one year ago
- 2= Somewhat better now than one year ago
- 3= About the same
- 4= Somewhat worse now than one year ago
- 5= Much worse now than one year ago



Time spent on informal caregiving

We would like to know how much time you spent on giving informal care to your care recipient. Please, consider the past week!

- TX_cg_ichh** Last week did you spent time on the activities below in your care recipient's house? Activities such as preparing food and drinks, cleaning the house, washing, ironing and sewing, shopping, maintenance work, odd job or gardening.
- 0= No
1= Yes
- TX_cg_ichh_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- TX_cg_icpc** Last week did you spent time on assisting your care recipient with the following activities: personal care (dressing/undressing, washing, combing, shaving), moving around in the house or going to the toilet, eating and drinking or taking medicines.
- 0= No
1= Yes
- TX_cg_icpc_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- TX_cg_icout** Last week did you spent time on assisting your care recipient with the following activities: moving or travelling outside the house (aid with walking or wheelchair), making trips and visiting family or friends, health care contacts (like visiting a doctor, the hospital), organizing help, aids, house adaptations or taking care of financial matters like insurance.
- 0= No
1= Yes
- TX_cg_icout_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- TX_cg_icoth** Does your care recipient receive help from other caregivers or volunteers besides you?
- 0 = No
1 = Yes
- TX_cg_icoth_hpw** If so, please indicate the time in hours per week.
- Range 1-168 hours



Self-rated Burden (SRB)

On the scale below, a “0” means that you feel that caring for or accompanying the care receiver at the moment is not hard at all; “10” means that you feel that caring for or accompanying the care receiver at the moment is much too hard. Please indicate with an “x” on the scale how burdensome you feel caring for or accompanying is at the moment.

0 1 2 3 4 5 6 7 8 9 10

Not at all straining Much too straining

Note: Make sure that the range from 0 to 10 is 100 mm long.

TX_cg_srb Annotate the number of mm from 0 to the X.
Range 0-100 mm



CarerQol

The following questions are about your situation as caregiver. Mark the box that describes your current situation best: 1) No 2) some or 3) a lot of

TX_cg_cq_care I have fulfillment with carrying out my care tasks.

- 1= No
- 2= Some
- 3 A lot of

TX_cg_cq_rel I have relational problems with the care receiver (e.g., he/she is very demanding, he/she behaves differently, we have communication problems).

- 1= No
- 2= Some
- 3= A lot of

TX_cg_cq_mh I have ... problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future).

- 1= No
- 2= Some
- 3= A lot of

TX_cg_cq_ph I have ... problems with my own physical health (e.g., more often sick, tiredness, physical stress).

- 1= No
- 2= Some
- 3= A lot of

TX_cg_cq_da I have ... problems combining my care tasks with my daily activities (e.g., household activities, work, study, family and leisure activities).

- 1= No
- 2= Some
- 3= A lot of

TX_cg_cq_fin I have ... financial problems because of my care tasks.

- 1= No
- 2= Some
- 3= A lot of

TX_cg_cq_sup I have ... support with carrying out my care tasks, when I need it (e.g., from family, friends, neighbors, acquaintances).

- 1= No
- 2= Some
- 3= A lot of



Please draw an “X” on the scale below to indicate how happy you feel currently

Completely unhappy 0 1 2 3 4 5 6 7 8 9 10 Completely happy

Note: Make sure that the range from 0 to 10 is 100 mm long.

TX_cg_cq_vas1 Annotate the number of mm from 0 to the X.
Range 0-100 mm

Imagine that you and your care receiver may pick someone who takes care of all the caregiving activities. This person will take over all the care activities at the care receivers’ home and it will cost nothing.

Please draw an “X” on the scale below to indicate how happy you feel if the caregiver activities will be taken care of by somebody else as described above.

Completely unhappy 0 1 2 3 4 5 6 7 8 9 10 Completely happy

TX_cg_cq_vas2 Annotate the number of mm from 0 to the X.
Range 0-100 mm



Quality of Life

The following questions concern your quality of life. In other words, how you rate your own life. E.g. whether you are satisfied with your life, or whether you enjoy your life or whether your life provides you satisfaction. Tick the box of the answer that best suits you.

TX_cg_QoL_gen

In general, how would you rate the quality of your life?

- 1 = Excellent
- 2 = Very Good
- 3 = Good
- 4 = Fair
- 5 = Poor

TX_cg_QoL_no

What mark would you give your life at this moment?

Range 0-10

TX_cg_QoL_1yrago

Compared to a year ago, how would you rate the quality of your life in general now ?

- 1 = Much better
- 2 = A little better
- 3 = About the same
- 4 = Slightly worse
- 5 = Much worse