

**CODE BOOK - CAREGIVER**  
***BASELINE MEASUREMENT - TO***

***TOPICS-MDS***

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

**TOPICS-MDS**



**Index**

Baseline and Follow-up measurements .....	2
General data .....	3
Health .....	5
Time spent on informal caregiving.....	6
Self-rated Burden (SRB).....	7
CarerQol .....	8
Quality of Life .....	10



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

## Baseline and Follow-up measurements

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

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

<b>ProjectID</b>	TOPICS-MDS study number
<b>PersonIDCG</b>	TOPICS-MDS individual ID of caregiver
<b>T0_cg_ses2006</b>	Baseline social economic status score 2006 of the caregiver
<b>T0_cg_ses2010</b>	Baseline social economic status score 2010 of the caregiver
<b>T0_cg_corop</b>	Corop code of the caregiver
<b>T0_cg_sted</b>	Urbanization degree of the caregiver
<b>T0_cg_prov</b>	Province of the caregiver
<b>T0_cg_ses2006cr*</b>	Baseline social economic status score 2006 of the care receiver
<b>T0_cg_ses2010cr*</b>	Baseline social economic status score 2010 of the care receiver
<b>T0_cg_coropcr*</b>	Corop code of the care receiver
<b>T0_cg_stedcr*</b>	Urbanization degree of the care receiver
<b>T0_cg_provcr*</b>	Province of the care receiver
<i>Please see <b>Appendix 1</b> for more information on the coding</i>	
<b>T0_cg_aafndat</b>	date on which the caregiver filled out the questionnaire dd/mm/yyyy
<i>Three additional variables were created:</i>	
<b>T0_cg_aafnday</b>	Day on which the caregiver filled out the questionnaire
<b>T0_cg_aafnmo</b>	Month on which the caregiver filled out the questionnaire
<b>T0_cg_aafnyr</b>	Year on which the caregiver filled out the questionnaire
<b>T0_cg_aques</b>	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
<b>T0_cg_agecr*</b>	Baseline age of <b>care receiver</b> on the date of filling out the questionnaire by caregiver
<b>T0_cg_asexcr*</b>	Sex of the <b>care receiver</b>
	0= Male
	1= Female
<b>T0_cg_age</b>	Baseline age of <b>caregiver</b> on the date of filling out the questionnaire
<b>T0_cg_asexcg</b>	Sex of the <b>caregiver</b>
	0 = Male
	1= Female

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



**T0\_cg\_arel** 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

**T0\_cg\_arelath** Other relationship with *care receiver*, namely...

**T0\_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](http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html))

**T0\_cg\_health1**                      In general, would you say your health is:

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

**T0\_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!

- T0\_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
- T0\_cg\_ichh\_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- T0\_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
- T0\_cg\_icpc\_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- T0\_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
- T0\_cg\_icout\_hpw** If you did, please indicate how much time you spent on the activities in hours per week.
- Range 1-168 hours
- T0\_cg\_icoth** Does your care recipient receive help from other caregivers or volunteers besides you?
- 0 = No  
1 = Yes
- T0\_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.

**TO\_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

**T0\_cg\_cq\_care** I have .... fulfillment with carrying out my care tasks.

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

**T0\_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

**T0\_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

**T0\_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

**T0\_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

**T0\_cg\_cq\_fin** I have ... financial problems because of my care tasks.

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

**T0\_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.*

**T0\_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

**T0\_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.

**T0\_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

**T0\_cg\_QoL\_no**

What mark would you give your life at this moment?

Range 0-10

**T0\_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