

CODE BOOK - CARE RECEIVER
BASELINE MEASUREMENT - T0

TOPICS-MDS

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

TOPICS-MDS





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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):

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
PersonIDCR	TOPICS-MDS individual ID of care receiver
T0_ses2006	Baseline social economic status score 2006 of care receiver
T0_ses2010	Baseline social economic status score 2010 of care receiver
T0_corop	COROP code of care receiver
T0_sted	Urbanization degree of care receiver
T0_prov	Province of care receiver
T0_gemcode	Municipality of care receiver
<i>Please see Appendix 1 for more information on the coding</i>	
T0_aafndat	Date on which the care receiver filled out the questionnaire dd/mm/yyyy
<i>Three additional variables were created:</i>	
T0_Aafnday	Day on which the care receiver filled out the questionnaire
T0_Aafnmo	Month in which the care receiver filled out the questionnaire
T0_Aafnyr	Year in which the care receiver filled out the questionnaire
T0_aques	Questionnaire is completed 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
T0_age	Age of care receiver on the date of filling out the questionnaire, calculated with self-reported birth date and date of filling out the questionnaire.
T0_asexe	Gender of yourself
	0= Male
	1= Female
T0_abc	In which country were you born?
	1= Netherlands
	2= Other country
T0_abcoth	Other country, namely
<i>Please see Appendix 1 for more information on the coding</i>	
T0_abcfath	In which country was your father born?
	1= Netherlands
	2= Other country



T0_abcfathoth Other country, namely

*Please see **Appendix 1** for more information on the coding*

T0_abcmoth In which country was your mother born?

1= Netherlands

2= Other country

T0_abcmothoth Other country, namely

*Please see **Appendix 1** for more information on the coding*

T0_aeducation What is the highest education you completed?

1= Less than 6 classes of primary school

2= 6 primary school classes

3= More than primary school / primary school with uncompleted further education

4= Practical training

5= Secondary vocational education

6= Pre-university education

7= University / higher professional education

T0_amarstat What is your marital status?

1= Married

2= Divorced

3= Widow / widower / partner deceased

4= Single

5= Sustainable living together, unmarried

T0_aliving What is your living arrangement/ situation?

1= Independent, alone

2= Independent, with others (partner, children etc.)

3= Home for the aged / residential care

4= Nursing home

T0_ahadat Date in home for the aged since dd/mm/yyyy

Three additional variables were created:

T0_Ahaday Day of date in home for the aged

T0_Ahamo Month of date in home for the aged

T0_Ahayr Year of date in home for the aged

T0_anhdat Date in nursing home since dd/mm/yyyy

Three additional variables were created:

T0_Anhday Day of date in nursing home

T0_Anhmo Month of date in nursing home

T0_Anhyr Year of date in nursing home



Health

The following questions are about your health. Tick the response that best suits you.

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

T0_health1

In general, would you say your health is:

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

T0_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



EQ-5D + C(ognitive dimension) (Without EQ VAS)

By placing a tick in one box in each group below, please indicate which statements best describes your own health state today.

T0_EQ5mo Mobility

- 1= I have no problems in walking about
- 2= I have some problems in walking about
- 3= I am confined to bed

T0_EQ5sc Self-care

- 1= I have no problems with washing or dressing myself
- 2= I have some problems in washing or dressing myself
- 3= I am unable to wash or dress myself

T0_EQ5act Activities (e.g. work, study, housework, family or leisure activities)

- 1= I have no problems with performing my usual activities
- 2= I have some problems with performing my usual activities
- 3= I am unable to perform my usual activities

T0_EQ5Pain Pain/discomfort

- 1= I have no pain or discomfort
- 2= I have moderate pain or discomfort
- 3= I have extreme pain or discomfort

T0_EQ5anx Anxiety/depression

- 1= I am not anxious or depressed
- 2= I am moderately anxious or depressed
- 3= I am extremely anxious or depressed

T0_EQ5c Cognitive functioning, such as memory, attention and thinking

- 1= I have no problems with my memory, attention and thinking
- 2= I have some problems with my memory, attention and thinking
- 3= I have serious problems with my memory, attention and thinking



Multimorbidity

The following questions are about the diseases and disorders that you have or have had. Please tick the boxes of the diseases or disorders you have or have had in the last 12 months. You can tick more than one answer.

In all 17 variables (T0_morb1 - T0_morb17) holds:

0= not ticked

1= ticked

T0_morb1	Diabetes
T0_morb2	Stroke, brain haemorrhage, cerebral infarction or TIA
T0_morb3	Heart failure
T0_morb4	A form of cancer (malignant disease)
T0_morb5	Asthma, chronic bronchitis, pulmonary emphysema or CARA / COPD
T0_morb6	Involuntary urinary loss (incontinence)
T0_morb7	Joint damage (osteoarthritis, rheumatoid wear) of hips or knees
T0_morb8	Osteoporosis (osteoporosis)
T0_morb9	Hip fracture
T0_morb10	Fractures other than hip
T0_morb11	Dizziness with falling
T0_morb12	Prostatism due to benign prostatic hyperplasia
T0_morb13	Depression
T0_morb14	Anxiety / panic disorder
T0_morb15	Dementia
T0_morb16	Hearing problems
T0_morb17	Vision disorders



Functioning (i)adl Katz-15

The following questions assess your functioning in activities of daily living. Please pick/ choose the answer that describes your current situation. Mark the box that describes your current situation best.

- | | |
|--|--|
| T0_katz_bath
0= no
1= yes | Do you need help with taking a bath or a shower? |
| T0_katz_dres
0= no
1= yes | Do you need help getting dressed? |
| T0_katz_brush
0= no
1= yes | Do you need help brushing your hair or shaving? |
| T0_katz_toil
0= no
1= yes | Do you need help toileting? |
| T0_katz_cont
0= no
1= yes | Do you use incontinence products? |
| T0_katz_transfer
0= no
1= yes | Do you need help sitting down and getting up from a chair? |
| T0_katz_walk
0= no
1= yes | Do you need help walking about? |
| T0_katz_eat
0= no
1= yes | Do you need help with eating? |
| T0_katz_tel
0= no
1= yes | Do you need help using the telephone? |
| T0_katz_travel
0= no
1= yes | Do you need help travelling? |



T0_katz_shop 0= no 1= yes	Do you need help shopping?
T0_katz_feed 0= no 1= yes	Do you need help preparing a meal?
T0_katz_hh 0= no 1= yes	Do you need help taking care of your house?
T0_katz_med 0= no 1= yes	Do you need help taking your medications?
T0_katz_fin 0= no 1= yes	Do you need help handling your finances?



Psychological Well-Being

These questions are about how you feel and how things have been with you **during the past month**. For each question, please give the one answer that comes closest to the way you have been feeling.

T0_PW_nerv How much of the time during the past month have you been very nervous?

- 1= All of the Time
- 2= Most of the Time
- 3= A good bit of the Time
- 4= Some of the Time
- 5= A little of the Time
- 6= None of the Time

T0_PW_calm How much of the time during the past month have you felt calm and peaceful?

- 1= All of the Time
- 2= Most of the Time
- 3= A good bit of the Time
- 4= Some of the Time
- 5= A little of the Time
- 6= None of the Time

T0_PW_blue How much of the time during the past month have you felt downhearted and blue?

- 1= All of the Time
- 2= Most of the Time
- 3= A good bit of the Time
- 4= Some of the Time
- 5= A little of the Time
- 6= None of the Time

T0_PW_happy How much of the time during the past month have you been a happy person?

- 1= All of the Time
- 2= Most of the Time
- 3= A good bit of the Time
- 4= Some of the Time
- 5= A little of the Time
- 6= None of the Time



T0_PW_down How much of the time during the past four weeks have you felt so down in the dumps that nothing could cheer you up?

- 1= All of the Time
- 2= Most of the Time
- 3= A good bit of the Time

- 4= Some of the Time
- 5= A little of the Time
- 6= None of the Time

Social Functioning

T0_socfunc During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups (like visiting friends or close relatives)?

- 1= All of the Time
- 2= Most of the Time
- 3= Some of the Time
- 4= A little of the Time
- 5= None of the Time



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_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_QoL_no

What mark would you give your life at this moment?

Range 0-10

T0_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



Use of care

T0_c_hosp Have you been hospitalized in the last 12 months?

0= No
1= Yes

T0_c_hospdays Number of days in hospital
Range 1-365 days

Hospital admission If yes, in which hospital?
Hospital location If yes, where is the hospital located?

In which participants have the opportunity to fill out five admissions:

T0_c_hosp1 Hospital admission 1

T0_c_hosploc1 Hospital location 1

... until

T0-c_hosp5 Hospital admission 5

T0-c_hosploc5 Hospital location 5

*Please see **Appendix 1** for more information on the coding*

T0_c_GP_lastXmo Did you visit the general practitioner or did the general practitioner visit you during evenings, nights or weekends over the last X months?

0= No
1= Yes

T0_c_GP_days Number of general practice visits or GP house calls
Range 1-365 days

T0_c_HC Do you have home care? For example nursing care, family care or domestic care.

0= No
1= Yes

T0_c_HC_hours Number of hours of home care per week
Range 1-168 hours

T0_c_HA_lastXmo Have you been admitted temporarily to a home for the aged in the last X months? E.g. because you were not able to go home immediately after discharge.

0= No
1= Yes

T0_c_HA_weeks Number of weeks in home of the aged?
Range 1-52 weeks



T0_c_NH_lastXmo 0= No 1= Yes	Have you been admitted temporarily to a nursing home in the last X months? E.g., because you were not able to go home immediately after discharge.
T0_c_NH_weeks Range 1-52 weeks	Number of weeks in nursing home?
T0_c_DCC 0= No 1= Yes	Do you visit a day care center (dagopvang in Dutch)?
T0_c_DCC_days Range 1-7 days	Number of days per week at day care center (dagopvang in Dutch)?
T0_c_OT 0= No 1= Yes	Do you visit a day care center (dagbehandeling in Dutch)?
T0_c_OT_days Range 1-7 days	Number of days per week a day care center (dagbehandeling in Dutch)?



Closure

T0_Help_ques Did someone help you fill out this questionnaire?

0= No, I have completed the list by myself.

1= Yes, someone helped me completing the list.

T0_Help_ques_which If yes, what help did you get?

1= Someone else has written down the answers, I have chosen the answers myself.

2= Someone else helped me to choose and write down the answers.

3= Someone else has chosen and written down the answers for me.