

# TOPICS-CEP

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*A composite endpoint used for relative effectiveness assessment in elderly care*

## Guidelines

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## 1. Summary

**In this guideline information can be found regarding the development and use of TOPICS-CEP.**

As part of the Dutch National Care for the Elderly Programme, the Older Persons Relevant Outcome of Care Score project established a composite endpoint (CEP) to assess the effectiveness of complex interventions in elderly care.

The CEP combines eight components derived from The Older Persons and

Informal Caregivers Survey – Minimum Data Set (TOPICS-MDS) into one single metric (called: TOPICS-CEP). The weights of the components are based on the health state preferences of older persons and informal caregivers.

Moreover, a secondary TOPICS-CEP was established based on the health state preferences of healthcare professionals. More detailed information can be found in chapter 9.

### **How to describe TOPICS-CEP:**

The TOPICS-CEP score is a preference-weighted index ranging from 0 (worst possible general wellbeing) to 10 (best possible general wellbeing) that combines 42 data points from TOPICS-MDS covered by eight components, such as functional limitations (Katz index of independence) **[1]** and emotional wellbeing (mental health subscale of the RAND-36) **[4]**. The components vary in both scale range and preference weight. More detailed information about the TOPICS-CEP can be found elsewhere ([www.topics-mds.eu](http://www.topics-mds.eu)).

## 2. Preface

The Dutch National Care for the Elderly Programme (NCEP) was established in 2008 to promote proactive, integrated healthcare for older persons with complex healthcare needs [5].

As part of this national agenda, The Older Persons and Informal Caregivers Survey Minimal DataSet (TOPICS-MDS) was developed to collect uniform information from all research projects funded under the Programme [6]. This public data repository is a collection of validated instruments measuring physical health and mental well-being of older persons (care receivers) and informal caregivers in the Netherlands, respectively [2, 3, 7, 8].

Longitudinal NCEP research projects participating in the TOPICS data sharing initiative (DSI) submitted baseline and at least one wave of follow-up data, typically 12 months after baseline data collection. Hence, TOPICS-MDS consists of pooled

data from various research projects which differ across study design, sampling framework, and inclusion criteria.

Even though the NCEP studies all collected baseline and follow-up data in a standardized manner it is a complex task to conduct comparative effectiveness research (CER) on this data because of the multiplicity issue of endpoints. As objective and subjective outcomes are available and may show outcomes in different directions the clinical relevance of overall value can be difficult to interpret. Hence, for optimal comparison of the NCEP projects' effectiveness a CEP that accounts for the relative importance of different outcomes is required.

This guideline is twofold. First, the establishment of the CEP is described. Then, the instructions on how to calculate the CEP scores are presented.

**Attention:**

The CEP that was established is meant for TOPICS-MDS questionnaire for care receivers (in this document referred to as: TOPICS-CR)[2, 3].

### 3. A composite endpoint to measure general well-being

CEPs are commonly used in randomized controlled clinical trials because they offer potential advantages, such as smaller sample size, shorter completion times and the summary measure for a treatment effect if more than one outcome is important.

A CEP consists of two or more components combined in one outcome. It represents an overall clinically relevant and valid measure of clinical benefit (effectiveness) due to treatment. CEPs usually refer to combined morbidity and mortality endpoints. However, it may also be a combination of objective outcomes and subjective patient reported outcomes (PROs).

**The Older Persons Relevant Outcome of Care Score project** aimed to establish a preference-weighted CEP for TOPICS-CR. The weights of the objective and subjective components included in the CEP (morbidity, functional limitations, emotional well-being, pain experience, cognitive problems, social functioning, self-perceived health, and self-perceived Quality of Life (QoL)) were to be based on the health state preferences of older persons and informal caregivers.

Valuation studies were conducted to obtain the weights for the CEP's components. The participants were older persons (n=124) and informal caregivers (n=76). More characteristics of the participants can be found in **Table 1**.

The vignettes (or profiles) used in the studies were based on cases derived from TOPICS-MDS data sharing initiative and contained information about the eight CEP components:

1. Morbidities
2. Functional limitations
3. Emotional well-being
4. Pain experience
5. Cognitive problems
6. Social functioning
7. Self-perceived health
8. Self-perceived QoL

The participants were asked to assess the general well-being (GWB) of a sample of vignette cases with scores ranging 0 to 10 (worst to best), which is in line with the Dutch grading system in school.

By means of mixed linear regression models the weights of the CEP's components were derived. Moreover, by means of including interaction terms in the models we compared the components' weights between older persons, informal caregivers, and healthcare professional. Interaction terms were also used to explore the influence of the factors: gender, age, and self-perceived health on the weights.

Primary results indicated that the weights of the CEP's components were not significantly different between older persons and informal caregivers. Consequently, we established one CEP based on the health state preferences of older persons and informal caregivers: TOPICS-CEP.

Additionally, secondary results indicated that our participants' age influenced the preference weights of the TOPICS-CEP's components. Therefore, we adjusted our preference weights based on the age distribution of older persons ( $\geq 65$  years) in the Netherlands [9]. The original and adjusted weights can be found in **Table 2**.

**Table 1**

Characteristics of the participants: Older persons (N=124) and informal caregivers (N=76).

	Older persons		Informal caregivers		Total	
	Mean	SD	Mean	SD	Mean	SD
Age	78.3	6.7	63.0	12.0	72.5	11.8
	N	%	N	%	N	%
Gender (female)	78	62.9	55	72.4	133	66.5
Self-perceived Health						
Excellent	8	6.5	1	1.3	9	4.5
Very good	16	13.0	13	17.1	29	14.5
Good	54	43.5	46	60.5	100	50.0
Reasonable	43	34.7	16	21.1	59	29.5
Poor	3	2.3	0	0.0	3	1.5

**Table 2**

The original TOPICS-CEP components' weights and the weights adjusted for the age distribution of older persons (≥ 65 years) in the Netherlands.

	Original CEP weights	Adjusted CEP weights
Intercept	9.03	9.00
Morbidities	-0.14	-0.13
Functional limitations	-0.12	-0.12
Emotional well-being	-0.04	-0.03
Pain experience	-0.04	-0.03
Cognitive problems	-0.13	-0.14
Social functioning	-0.01	-0.01
Self-perceived Health	-0.16	-0.17
Self-perceived QoL	-0.03	-0.02

## 4. Components included in TOPICS-CEP

TOPICS-CR contains 51 questions of which 26 are included in the calculation of TOPICS-CEP. In this guideline we only describe the questions and items included in TOPICS-CEP.

**Table 3** provides an overview of the TOPICS-CEP components and the questions of TOPICS-CR that are associated with these components.

**Table 3**

TOPICS-CEP components and TOPICS-CR questions.

CEP-Component	TOPICS-CR question	Number of levels per attribute
Morbidities	18 (a-q)	2
Functional limitations	19 – 33	2
Emotional well-being	34 – 38	6
Pain experience	15	3
Cognitive problems	17	3
Social functioning	39	5
Self-perceived health	10	5
Self-perceived QoL	40	5

1. The TOPICS-CEP component *Morbidities* includes one item from the original TOPICS-CR. The included conditions were based on a listing widely used in the Netherlands to record multi-morbidity [10]. Respondents are asked to indicate morbidities experienced in the last twelve months from 17 pre-defined conditions. The attributes are scored 0 (have not experienced) or 1 (have experienced)
2. The TOPICS-CEP component *Functional limitations* includes 15 items from the original TOPICS-CR. The extent of functional limitation was measured using a modified version of the Katz index [1]. Respondents are asked to indicate whether they need assistance in various tasks and activities in daily life. The attributes are scored 0 (do not need assistance) or 1 (need assistance).



**Continuation of Table 3**

3. The TOPICS-CEP component *Emotional well-being* includes 5 items from the original TOPICS-CR. The Rand-36 mental health sub-scale was utilised to assess emotional well-being in TOPICS-CR **[4]**. Respondents are asked to indicate how often in the past four weeks they have felt: (1) nervous, (2) calm and peaceful, (3) down-hearted and blue, (4) happy, and (5) so down in the dumps nothing could cheer them up. The attributes are scored from 1 (always) to 6 (never).
4. The TOPICS-CEP component *Pain experience* includes 1 item from the original TOPICS-CR. Pain experience was measured using the EQ5-D pain item **[11]**. Respondents are asked to indicate the level of pain they experience today. The attribute is scored from 1 (no pain) to 3 (severe pain).
5. The TOPICS-CEP component *Cognitive problems* includes 1 item from the original TOPICS-CR. Cognitive problems was measured using the EQ5D+C cognition attribute **[11]**. Respondents are asked to indicate the level of cognitive problems. The attribute is scores from 1 (no problems) to 3 (severe problems).
6. The TOPICS-CEP component *Social functioning* includes 1 item from the original TOPICS-CR. Social functioning was determined by 1 question derived from the RAND-36 **[4]**. Respondents are asked to indicate how often in the past four weeks their physical health or emotional problems had hampered their social activities. The attribute was score from 1 (continuously) to 5 (never).
7. The TOPICS-CEP component *Self-perceived health* includes 1 item from the original TOPICS-CR. The RAND-36 self-perceived health question was utilised to assess self-perceived health in TOPICS-CR **[4]**. Respondents are asked to rate their current health state on a level from 1 (excellent) to 5 (poor).
8. The TOPICS-CEP component *Self-perceived health* includes 1 item from the original TOPICS-CR. The question was formed using phrasing similar to the self-perceived health question form the RAND-36 **[4]**. Respondents are asked to rate their current quality of life on a level from 1 (excellent) to 5 (poor).

## 5a. Calculating TOPICS-CEP

The TOPICS-CEP scores are established in four steps:

**1. Reverse scoring of items (Table 4)**

*TOPICS items are positively- and negatively keyed. Reverse the scores of the emotional well-being items: down, blue and nervous and the social functioning item. This way all the data items are keyed negatively; a higher score indicates a worse condition.*

**2. Aggregation of items (Table 4)**

*Each of the CEP components morbidities, functional limitations, and emotional well-being consists of data from multiple TOPICS items. Calculate from these individual*

*items three summary items: number of morbidities, number of functional limitations, and emotional well-being score.*

**3. Calculation of the raw CEP scores (Table 5)**

*Use the preference weights to calculate the raw TOPICS-CEP scores.*

**4. Transforming the CEP scores linearly to a common metric with a possible range of 0-10 (Box 1)**

*Transform the raw TOPICS-CEP scores into indexed scores (0-10).*

**Table 4**

Recoding and aggregating TOPICS-CEP items.

Items to be recoded	Recoding
Q34, 36, 38	(1=6) (2=5) (3=4) (4=3) (5=2) (6=1)
Q39	(1=5) (2=4) (3=3) (4=2) (5=1)
TOPICS-CEP components	Aggregation of the items
Morbidities	18a+18b+18c+18d+18e+18f+18g+18h+18i+18j+18k+18l+18m+18n+18o+18p+18q
Functional limitations	19+20+21+22+23+24+25+26+27+28+29+30+31+32+33
Emotional well-being	34+35+36+37+38
Pain experience	15
Cognitive problems	17
Social functioning	39
Self-perceived health	10
Self-perceive QoL	40

**Table 5**

Calculating the raw TOPICS-CEP score.

TOPICS-CEP components	Weights
Intercept	9.00
Morbidities	-0.13
Functional limitations	-0.12
Emotional well-being	-0.03
Pain experience	-0.03
Cognitive problems	-0.14
Social functioning	-0.01
Self-perceived health	-0.17
Self-perceive QoL	-0.02

*Example:*

*Someone has 3 out of the 17 predefined conditions; needs assistance with 4 out of 15 predefined tasks; has a raw emotional well-being score of 9; experience severe pain (3); has moderate cognitive problems (2); has never had to cancel a social activity because of physical health or emotional problems (1); perceives own health as "reasonable" (4); and perceives own quality of life as "good" (3).*

$$9.00 + [-0.13*3] + [-0.12*4] + [-0.03*9] + [-0.03*3] + [-0.14*2] + [-0.01*1] + [-0.17*4] + [-0.02*3] = \mathbf{6.74}$$

**Box 1**

Calculating the indexed TOPICS-CEP score (index: 0-10).

Minimum raw TOPICS-CEP score = 2.58  
 Maximum raw TOPICS-CEP score = 8.48  
 Score range = 5.90

$$\frac{(\text{Raw TOPICS-CEP score} - \text{Minimum raw TOPICS-CEP score})}{\text{Score range}} \times 10$$

*Example:*

*When the raw TOPICS-CEP score = 6.74  
 The indexed TOPICS-CEP score = [(6.74-2.58)/5.90] x 10 = **7.05***

## 5b. SPSS syntax

In case you have used TOPICS-CR to collect data from your participants and used the TOPICS-CR codebook (data dictionary) to name and label the variables you can run the syntaxes to establish the TOPICS-CEP scores [12].

In **Box 2** the syntaxes to reverse scoring of the items can be found. **Box 3** provides the syntaxes that can be used to aggregate the items from Morbidities, Functional limitations and Emotional well-being.

**Boxes 4 and 5** contain the syntaxes to calculate the raw and indexed TOPICS-CEP score, respectively.

**Attention:** These syntaxes are written to use on TOPICS-CR baseline data. In case you want to calculate TOPICS-CEP for the follow-up data: Find "T0" and replace with "T6" when it is follow-up after 6 months, "T12" when it is follow-up after 12 months and so forth [13].

### Box 2

```
Reverse scoring of items
*** (Q34 + 36 + 38)***.
RECODE TO_PW_NERV (1=6) (2=5) (3=4) (4=3) (5=2) (6=1) (ELSE=SYSMIS) INTO
TO_PW_NERV_REVERSED.
RECODE TO_PW_BLUE (1=6) (2=5) (3=4) (4=3) (5=2) (6=1) (ELSE=SYSMIS) INTO
TO_PW_BLUE_REVERSED.
RECODE TO_PW_DOWN (1=6) (2=5) (3=4) (4=3) (5=2) (6=1) (ELSE=SYSMIS) INTO
TO_PW_DOWN_REVERSED.
EXECUTE.

RECODE TO_PW_NERV_REVERSED (SYSMIS=9999).
RECODE TO_PW_BLUE_REVERSED (SYSMIS=9999).
RECODE TO_PW_DOWN_REVERSED (SYSMIS=9999).
EXECUTE.

MISSING VALUES
TO_PW_NERV_REVERSED TO_PW_BLUE_REVERSED TO_PW_DOWN_REVERSED (9999).
EXECUTE.

VARIABLE LABELS
TO_PW_NERV_REVERSED 'Nervous prepared for raw emotional wellbeing score'/
TO_PW_BLUE_REVERSED 'Blue prepared for raw emotional well-being score'/
TO_PW_DOWN_REVERSED 'Down prepared for raw emotional well-being score'.
EXECUTE.

*** (Q39)***.
RECODE TO_SOCFUNC (1=5) (2=4) (3=3) (4=2) (5=1) (ELSE=SYSMIS) INTO
TO_SOCFUNC_REVERSED.
EXECUTE.

RECODE TO_SOCFUNC_REVERSED (SYSMIS=9999).
EXECUTE.

MISSING VALUES
TO_SOCFUNC_REVERSED (9999).

VARIABLE LABELS
TO_SocFunc_REVERSED 'Social functioning prepared for CEP calculation'.
EXECUTE.
```

**Box 3**

Aggregating of items

\*\*\*Q18a to Q18q\*\*\*.

COMPUTE

T0\_MORB17\_SUM=T0\_MORB1+T0\_MORB2+T0\_MORB3+T0\_MORB4+T0\_MORB5+T0\_MORB6+  
T0\_MORB7+T0\_MORB8+T0\_MORB9+T0\_MORB10+T0\_MORB11+T0\_MORB12+T0\_MORB13+T0\_MOR  
B14+T0\_MORB15+T0\_MORB16+T0\_MORB17.

EXECUTE.

RECODE T0\_MORB17\_SUM (SYSMIS=9999).

MISSING VALUES T0\_MORB17\_SUM (9999).

VARIABLE LABELS T0\_MORB17\_SUM 'Sum score MORBIDITIES baseline'.

EXECUTE.

\*\*\*Q19 to Q33\*\*\*.

COMPUTE

T0\_Katz15\_sum=T0\_KATZ\_BATH+T0\_KATZ\_DRES+T0\_KATZ\_BRUSH+T0\_KATZ\_TOIL+T0\_KATZ\_CONT+T  
0\_KATZ\_TRANSFER+T0\_KATZ\_WALK+T0\_KATZ\_EAT+T0\_KATZ\_TEL+T0\_KATZ\_TRAVEL+T0\_KATZ\_SHOP+  
T0\_KATZ\_FEED+T0\_KATZ\_HH+T0\_KATZ\_MED+T0\_KATZ\_FIN.

EXECUTE.

RECODE T0\_KATZ15\_SUM (SYSMIS=9999).

MISSING VALUES T0\_KATZ15\_SUM (9999).

VARIABLE LABELS T0\_katz15\_sum 'Sum score ADL/iADL baseline'.

EXECUTE.

\*\*\*Q34 to Q38\*\*\*.

COMPUTE

T0\_PW\_SUM=T0\_PW\_NERV\_REVERSED+T0\_PW\_BLUE\_REVERSED+T0\_PW\_DOWN\_REVERSED+  
T0\_PW\_CALM+T0\_PW\_HAPPY.

EXECUTE.

RECODE T0\_PW\_SUM (SYSMIS=9999).

MISSING VALUES T0\_PW\_SUM (9999).

VARIABLE LABELS T0\_PW\_SUM 'Raw emotional well-being score baseline'.

EXECUTE.

**Box 4**

Calculating the raw TOPICS-CEP scores.

COMPUTE

T0\_TOPICS\_CEP\_Raw=9.00+(-0.13\*T0\_MORB17\_SUM)+(-0.12\*T0\_KATZ15\_SUM)+(-  
0.03\*T0\_PW\_SUM)+(-0.03\*T0\_EQ5PAIN)+(-0.14\*T0\_EQ5C)+(-0.01\*T0\_SOCFUNC\_REVERSED)+(-  
0.17\*T0\_HEALTH1)+(-0.02\*T0\_QOL\_GEN).

EXECUTE.

RECODE T0\_TOPICS\_CEP\_Raw (SYSMIS=9999).

MISSING VALUES T0\_TOPICS\_CEP\_Raw (9999).

VARIABLE LABELS T0\_TOPICS\_CEP\_Raw 'Raw Composite endpoint based at baseline; PW  
older persons and informal caregivers'.

EXECUTE.

**Box 5**

Calculating the indexed TOPICS-CEP scores.

COMPUTE

T0\_TOPICS\_CEP =((T0\_TOPICS\_CEP\_Raw-2.58)/(8.48-2.58))\*10.

EXECUTE.

RECODE T0\_TOPICS\_CEP (SYSMIS=9999).

MISSING VALUES T0\_TOPICS\_CEP (9999).

VARIABLE LABELS T0\_TOPICS\_CEP 'Indexed composite endpoint at baseline: PW older persons and informal caregivers scaled from 0 to 10'.

EXECUTE.

## 6a. Calculating TOPICS-CEP without Morbidities (TOPICS-CEP-7)

The TOPICS-CR follow-up instrument does not include the health domain Morbidities. In this section we will briefly describe how to calculate TOPICS-CEP without the component morbidities. This complementary CEP is referred to as TOPICS-CEP-C (C=Complementary)

The TOPICS-CEP scores are established in the same four steps. However, other preference weights for the TOPICS-CEP components are used. Consequently, the

minimum and maximum raw scores are slightly different, hence, we adjusted the algorithm to calculate the Indexed TOPICS-CEP scores.

**Attention:** we advise you to either use the TOPICS-CEP with morbidities for both baseline and follow-up OR use TOPICS-CEP without morbidities for both baseline and follow-up. HENCE, do not compare TOPICS-CEP with morbidity in baseline with TOPICS-CEP without morbidity in follow-up!

**Table 6**

Recoding and aggregating TOPICS-CEP items without morbidities (TOPICS-CEP-7).

Items to be recoded	Recoding
Q34, 36, 38	(1=6) (2=5) (3=4) (4=3) (5=2) (6=1)
Q39	(1=5) (2=4) (3=3) (4=2) (5=1)
TOPICS-CEP components	Aggregation of the items
Functional limitations	19+20+21+22+23+24+25+26+27+28+29+30+31+32+33
Emotional well-being	34+35+36+37+38
Pain experience	15
Cognitive problems	17
Social functioning	39
Self-perceived health	10
Self-perceive QoL	40

**Table 7**

Calculating the raw TOPICS-CEP score without morbidities (TOPICS-CEP-7).

TOPICS-CEP components	Weights adjusted for age distribution in the Netherlands
Intercept	9.24
Functional limitations	-0.13
Emotional well-being	-0.04
Pain experience	-0.21
Cognitive problems	0.41
Social functioning	-0.06
Self-perceived health	-0.19
Self-perceive QoL	-0.01

*Example:*

Someone needs assistance with 4 out of 15 predefined tasks; has a raw emotional well-being score of 9; experience severe pain (3); has moderate cognitive problems (2); has never had to cancel a social activity because of physical health or emotional problems (1); perceives own health as "reasonable" (4); and perceives own quality of life as "good" (3).

$$9.29 + [-0.13*4] + [-0.04*9] + [-0.21*3] + [+0.41*2] + [-0.06*1] + [-0.19*4] + [-0.01*3] = 7.70$$

**Box 6**

Calculating the indexed TOPICS-CEP score (index: 0-10) without morbidities.

Minimum raw TOPICS-CEP score without morbidities = 4.57  
 Maximum raw TOPICS-CEP score without morbidities = 9.80  
 Score range = 5.23

$$\frac{(\text{Raw TOPICS-CEP score} - \text{Minimum raw TOPICS-CEP score})}{\text{Score range}} \times 10$$

*Example:*

When the raw TOPICS-CEP score without morbidities = 7.70  
 The indexed TOPICS-CEP score without morbidities =  $[(7.70-4.57)/5.23] \times 10 = 5.98$



## 6b. SPSS syntax

In case you have used TOPICS-CR to collect data from your participants and used the TOPICS-CR codebook (data dictionary) to name and label the variables you can run the syntaxes to establish the TOPICS-CEP scores [12].

In **Box 2** (page 11) the syntaxes to reverse scoring of the items can be found. **Box 3** (page 12) provides the syntaxes that can be used to aggregate the items from Functional limitations and Emotional well-being.

**Boxes 7 and 8** contain the syntaxes to calculate the raw and indexed TOPICS-CEP score without the component "Morbidities", respectively.

**Attention:** These syntaxes are written to use on TOPICS-CR baseline data. In case you want to calculate TOPICS-CEP for the follow-up data: Find "T0" and replace with "T6" when it is follow-up after 6 months, "T12" when it is follow-up after 12 months and so forth [13].

### Box 7

Calculating the raw TOPICS-CEP scores without morbidities (TOPICS-CEP-7).

```
COMPUTE
TO_TOPICS_CEP_7_RAW=9.24+(-0.13*TO_KATZ15_SUM)+(-0.04*TO_PW_SUM)+
(-0.21*TO_EQ5PAIN)+(0.41*TO_EQ5C)+(-0.06*TO_SOCFUNC_REVERSED)+(-0.19*TO_HEALTH1)+(-
0.01*TO_QOL_GEN).
EXECUTE.

RECODE TO_TOPICS_CEP_7_RAW (SYSMIS=9999).
MISSING VALUES TO_TOPICS_CEP_7_RAW (9999).
VARIABLE LABELS TO_TOPICS_CEP_7_RAW 'Raw Composite endpoint at baseline; without
morbidities'.
EXECUTE.
```

### Box 8

Calculating the Indexed TOPICS-CEP scores without morbidities (TOPICS-CEP-7)

```
COMPUTE
TO_TOPICS_CEP_7 =(( TO_TOPICS_CEP_7_RAW-4.57)/(9.80-4.57))*10.
EXECUTE.

RECODE TO_TOPICS_CEP_7 (SYSMIS=9999).
MISSING VALUES TO_TOPICS_CEP_7 (9999).
VARIABLE LABELS TO_TOPICS_CEP_7 'Indexed Composite endpoint at baseline; without
morbidities'.
EXECUTE.
```

## 7a. Calculating Secondary TOPICS-CEP (TOPICS-CEP-S)

The aim of the OPROCS project was to establish a preference-weighted CEP for TOPICS-CR. The primary TOPICS-CEP score is based on the health state preferences of older persons and informal caregivers (see previous chapters). However, we performed a second valuation study to derive the TOPICS-CEP components' weights based on the health state preferences of healthcare professionals.

Our results indicated that the weights of TOPICS-CEP components did not differ significantly between the various healthcare disciplines; **Table 8** shows professionals' discipline included in our study. However, the weights based on the health state preferences of healthcare professionals differed significantly from those of older persons and informal caregivers. Subsequently, a secondary

TOPICS-CEP score can be calculated based on the health state preferences of healthcare professionals. This CEP will be referred to as TOPICS-CEP-S (S=secondary).

The secondary TOPICS-CEP scores are established in the same four steps as the primary TOPICS-CEP scores. The first two steps (reverse scoring of items and aggregation of items) are similar to establishing the primary TOPICS-CEP scores (**Table 4** (page 9), **Box 2** (page 11), and **Box 3** (page 12)).

However, other preference weights for the TOPICS-CEP components are used (**Table 9**). Consequently, the minimum and maximum raw scores are slightly different, hence, we adjusted the algorithm to calculate the Indexed TOPICS-CEP scores (**Box 7**).

**Table 8**

Characteristics of the participants: Healthcare professionals (N=330)

	N	%	N	%
Doctors	127	38.5		
General Practitioner			32	25.2
Nursing home physician			43	33.9
Internist			13	10.2
Geriatrician			39	30.7
Nurses	102	30.9		
Welfare staff	45	13.6		
Allied health professionals	56	17.0		
<i>Total</i>	330	100	127	100

**Table 9**

Calculating the raw secondary TOPICS-CEP score (TOPICS-CEP-S).

TOPICS-CEP components	Weights
Intercept	10.47
Morbidities	-0.02
Functional limitations	-0.05
Emotional well-being	-0.05
Pain experience	-0.18
Cognitive problems	-0.12
Social functioning	-0.16
Self-perceived health	-0.18
Self-perceive QoL	-0.28

*Example:*

Someone has 3 out of the 17 predefined conditions; needs assistance with 4 out of 15 predefined tasks; has a raw emotional well-being score of 9; experience severe pain (3); has moderate cognitive problems (2); has never had to cancel a social activity because of physical health or emotional problems (1); perceives own health as “reasonable” (4); and perceives own quality of life as “good” (3).

$$10.47 + [-0.02*3] + [-0.05*4] + [-0.05*9] + [-0.18*3] + [-0.12*2] + [-0.16*1] + [-0.18*4] + [-0.28*3] = \mathbf{7.26}$$

**Box 9**

Calculating the indexed secondary TOPICS-CEP score (TOPICS-CEP-S) (index: 0-10).

Minimum raw secondary TOPICS-CEP score = 3.88

Maximum raw secondary TOPICS-CEP score = 9.30

Score range = 5.42

$$\frac{(\text{Raw TOPICS-CEP score} - \text{Minimum raw TOPICS-CEP score})}{\text{Score range}} \times 10$$

*Example:*

When the raw secondary TOPICS-CEP score = 7.26

The indexed secondary TOPICS-CEP score =  $[(7.26-3.88)/5.42] \times 10 = \mathbf{6.24}$

## 7b. SPSS Syntax

In case you have used TOPICS-CR to collect data from your participants and used the TOPICS-CR codebook (data dictionary) to name and label the variables you can run the syntaxes to establish the TOPICS-CEP scores [12].

In **Box 2** (page 11) the syntaxes to reverse scoring of the items can be found. **Box 3** (page 12) provides the syntaxes that can be used to aggregate the items from Morbidities, Functional limitations and Emotional well-being.

**Boxes 7 and 8** contain the syntaxes to calculate the raw and indexed TOPICS-CEP score, respectively.

**Attention:** These syntaxes are written to use on TOPICS-CR baseline data. In case you want to calculate TOPICS-CEP for the follow-up data: Find "T0" and replace with "T6" when it is follow-up after 6 months, "T12" when it is follow-up after 12 months and so forth [13].

### Box 10

Calculating the raw secondary TOPICS-CEP-S scores.

```
COMPUTE
T0_TOPICS_CEP_S_Raw =10.47+(-0.02*T0_MORB17_SUM)+(-0.05*T0_KATZ15_SUM)+(-
0.05*T0_PW_SUM)+(-0.18*T0_EQ5PAIN)+(-0.12*T0_EQ5C)+(-0.16*T0_SOCFUNC_REVERSED)+(-
0.18*T0_HEALTH1)+(-0.28*T0_QOL_GEN).
EXECUTE.

RECODE T0_TOPICS_CEP_S_Raw (SYSMIS=9999).
MISSING VALUES T0_TOPICS_CEP_S_Raw (9999).
VARIABLE LABELS T0_TOPICS_CEP_S_Raw 'Raw secondary composite endpoint at baseline;
PW healthcare professionals'.
EXECUTE.
```

### Box 11

Calculating the indexed secondary TOPICS-CEP-S scores.

```
COMPUTE
T0_TOPICS_CEP_S=(( T0_TOPICS_CEP_S_Raw-3.88)/(9.25-3.88))*10.
EXECUTE.

RECODE T0_TOPICS_CEP_S (SYSMIS=9999).
MISSING VALUES T0_TOPICS_CEP_S (9999).
VARIABLE LABELS T0_TOPICS_CEP_S 'Indexed secondary composite endpoint at baselinePW
healthcare professionals scaled from 0 to 10'.
EXECUTE.
```

## 8. Further reading

On the website: [www.TOPICS-MDS.eu](http://www.TOPICS-MDS.eu) you can find:

- TOPICS-MDS questionnaires
- TOPICS-MDS codebooks / dictionaries
- These guidelines for TOPICS-CEP
- References of scientific publications relating to TOPICS-MDS and/or TOPICS-CEP

## 9. References

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13. *The Older Persons and Informal Caregivers Survey for Care Receivers - Follow up - Data dictionary* [cited 2013 25 November]; Available from: [http://topics-mds.nl/wordpress/wp-content/uploads/2013/09/Follow-up-Dictionary\\_Participant.pdf](http://topics-mds.nl/wordpress/wp-content/uploads/2013/09/Follow-up-Dictionary_Participant.pdf).

## Appendix 1: Short version of Questionnaire

As stated previously not all items from TOPICS-CR are used to calculate TOPICS-CEP score. In this section you can find the questions from TOPICS-CR that needs to be used to calculate TOPICS-CEP.

### 1. Morbidities

Please indicate whether you have suffered from these illnesses or conditions over the last 12 months.

		Yes, I have (1)	No, I haven't (0)
A	Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
B	Stroke, cerebral haemorrhage (bleed in the brain), cerebral infarction (blocked blood vessel in the brain) or TIA	<input type="checkbox"/>	<input type="checkbox"/>
C	Heart failure	<input type="checkbox"/>	<input type="checkbox"/>
D	A type of cancer (malignant condition)	<input type="checkbox"/>	<input type="checkbox"/>
E	Asthma, chronic bronchitis, lung emphysema or COPD	<input type="checkbox"/>	<input type="checkbox"/>
F	Involuntary loss of urine (incontinence)	<input type="checkbox"/>	<input type="checkbox"/>
G	Wearing of the joints (arthrosis, degenerative arthritis) of hips or knees	<input type="checkbox"/>	<input type="checkbox"/>
H	Loss of bone tissue (osteoporosis)	<input type="checkbox"/>	<input type="checkbox"/>
I	Broken hip	<input type="checkbox"/>	<input type="checkbox"/>
J	Broken bones other than a broken hip	<input type="checkbox"/>	<input type="checkbox"/>
K	Dizziness with falling	<input type="checkbox"/>	<input type="checkbox"/>
L	Prostate symptoms caused by benign prostate enlargement	<input type="checkbox"/>	<input type="checkbox"/>
M	Depression	<input type="checkbox"/>	<input type="checkbox"/>
N	Anxiety / panic disorder	<input type="checkbox"/>	<input type="checkbox"/>
O	Dementia	<input type="checkbox"/>	<input type="checkbox"/>
P	Hearing problems	<input type="checkbox"/>	<input type="checkbox"/>
Q	Problems with vision	<input type="checkbox"/>	<input type="checkbox"/>

## 2. Daily functioning

Please check the appropriate box to indicate whether you do or do not need help with each of these tasks. Select your answer according to the situation as it is at the moment.

		Yes, I need help (1)	No, I do not need help (0)
A	Do you need help with <i>bathing or showering</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you need help with <i>getting dressed</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
C	Do you need help with <i>combing your hair or with shaving</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you need help with <i>going to the toilet</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
E	Do you use <i>incontinence products</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
F	Do you need help with <i>getting up from a chair</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
G	Do you need help with <i>walking</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
H	Do you need help with <i>eating</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
I	Do you need help with <i>using the telephone</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
J	Do you need help with <i>travelling</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
K	Do you need help with <i>grocery shopping</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
L	Do you need help with <i>preparing a meal</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
M	Do you need help with <i>household tasks</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
N	Do you need help with <i>taking your medicines</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
O	Do you need help in <i>dealing with finances</i> ?	<input type="checkbox"/>	<input type="checkbox"/>



### 3. Emotional well-being

Please check the appropriate box to indicate how you have been feeling the past month.

---

#### 3a. How often in the past month have you been very nervous?

Never	Almost	Sometimes	Quite often	Very often	Always
(1)	(2)	(3)	(4)	(5)	(6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### 3b. How often in the past month have you felt calm and tranquil?

Never	Almost	Sometimes	Quite often	Very often	Always
(1)	(2)	(3)	(4)	(5)	(6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### 3c. How often in the past month have you felt despondent and sombre?

Never	Almost	Sometimes	Quite often	Very often	Always
(1)	(2)	(3)	(4)	(5)	(6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### 3d. How often in the past month have you felt happy?

Never	Almost	Sometimes	Quite often	Very often	Always
(1)	(2)	(3)	(4)	(5)	(6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3e. How often in the past month have you felt so sombre that nothing could cheer you up?**

Never	Almost	Sometimes	Quite often	Very often	Always
(1)	(2)	(3)	(4)	(5)	(6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check the appropriate boxes. Select your answer according to the situation as it is at the moment.

**4. Pain experience**

**Do you experience any pain or other symptoms?**

- I have no pain or other symptoms (1)
- I have moderate pain or other symptoms (2)
- I have very severe pain or other symptoms (3)

**5. Cognitive problems**

**Do you have any problems with memory, attention and thinking?**

- I have no problems with my memory, attention and thinking (1)
- I have some problems with my memory, attention and thinking (2)
- I have severe problems with my memory, attention and thinking (3)

**6. Social functioning**

**How often in the past 4 weeks have your physical health or emotional problems hampered your social activities (such as visits to friends or close family members)?**

- Continuously (5)
- Mostly (4)
- Sometimes (3)
- Rarely (2)
- Never (1)

## 7. Self-perceived health

### How is your health in general?

- Excellent (1)
- Very good (2)
- Good (3)
- Reasonable (4)
- Poor (5)

## 8. Self-perceived quality of life\*

*"Quality of life" refers to what you think about your life. For example, whether you are satisfied with your life, whether you have enjoyment in your life and whether your life gives you satisfaction.*

### How is your quality of life in general?

- Excellent (1)
- Very good (2)
- Good (3)
- Reasonable (4)
- Poor (5)

\*\*\*\*\*

*This is the end of this questionnaire.*

*Thank you for your cooperation.*

## Appendix 2: Scoring of short version

**Table 10**

Recoding and aggregating TOPICS-CEP items (Short form).

Items to be recoded	Recoding
Q3a, 3c, 3e	(1=6) (2=5) (3=4) (4=3) (5=2) (6=1)
Q6	(1=5) (2=4) (3=3) (4=2) (5=1)

  

TOPICS-CEP components	Aggregation of the items	Weights
Intercept		9.00
Morbidities	1a+1b+1c+1d+1e+1f+1g+1h+1i+1j +1k+1l+1m+1n+ 1o+1p+1q	-0.13
Functional limitations	2a+2b+2c+2d+2e+2f+2g+2h+2i+2j +2k+2l+2m+2n+2o+2p+2q	-0.12
Emotional well-being	3a+3b+3c+3d+3e	-0.03
Pain experience	4	-0.03
Cognitive problems	5	-0.14
Social functioning	6	0.00
Self-perceived health	7	-0.17
Self-perceive QoL	8	-0.02

**Box 10**

Calculating the indexed TOPICS-CEP score (index: 0-10).

Minimum raw secondary TOPICS-CEP score = 2.58  
 Maximum raw secondary TOPICS-CEP score = 8.48  
 Score range = 5.90

$$\frac{\text{Raw TOPICS-CEP score} - 2.58}{5.90} \times 10$$

## Appendix 3: Brief description of calculating TOPICS-CEP

### Citation from our valuation paper (in process):

Briefly, the TOPICS-CEP score is established in four steps. Firstly, to key all data points in the same direction the social functioning item and emotional wellbeing items down, blue, and nervous are reverse scored. Secondly, all items that belong to the same health domain are aggregated into one component. Thus, 17 morbidity items are combined into the component *number of morbidities*, 15 items regarding functional limitations into *number of functional limitations*, and 5 emotional wellbeing items into *raw emotional well-being score*. Thirdly, a raw TOPICS-CEP score is calculated by means of applying the preference weights for the Dutch population aged 65 years and over. The raw TOPICS-CEP score = 9.00 (Intercept) – [0.13 x number of morbidities (list of 17 pre-defined conditions widely used in the Netherlands)] – [0.12 x number of functional limitations (Katz index of independence)] – [0.03 x raw emotional wellbeing score (mental health subscale of the RAND-36)] – [0.03 x level of pain experience (pain dimension of the EQ-5D)] – [0.14 x cognitive problems (cognition dimension of the EQ-5D+C)] – [0.01 x level of social functioning (item 10 from the RAND-36)] – [0.17 x level of self-perceived health (item 1 from the RAND-36)] – [0.02 x level of self-perceived quality of life (phrasing similar to self-perceived health item from the RAND-36)]. Finally, the raw TOPICS-CEP score is transformed into an indexed score (referred to as TOPICS-CEP score) ranging 0 to 10. The TOPICS-CEP score = [(raw TOPICS-CEP score – 2.58)/5.90] x 10.