

## Patient-reported Outcomes in Cognitive Impairment (PROCOG)

Frank, L., Flynn, J. A., Kleinman, L., Margolis, M. K., Matza, L. S., Beck, C., and Bowman, L. (2006)

"Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment."

Meetinstrument	Patient-reported outcomes in cognitive impairment
Afkorting	PROCOG
Auteur	Frank L.
Onderwerp	Beoordeling van cognitieve stoornissen
Doelstellingen	Beoordeling van symptomen van licht cognitief deficit en dementie van het Alzheimer type en hun invloed op de kwaliteit van het functioneren en het gedrag in verband met de gezondheid en de dagdagelijkse activiteiten.
Populatie	Patiënten met lichte tot matige cognitieve stoornissen
Afname	Auto-rapportage
Aantal items	55
Deelname van de patiënt	Ja; zelf uitgevoerde test
Localisation de l'instrument de mesure	Frank, L., Flynn, J. A., Kleinman, L., Margolis, M. K., Matza, L. S., Beck, C., and Bowman, L. 2006. "Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment." <i>Int Psychogeriatr.</i> 18(1):135-49

### Doelstellingen

De PROCOG werd ontworpen om de symptomen van licht cognitief deficit en dementie van het Alzheimer type te beoordelen en hun invloed op de kwaliteit van het functioneren en het gedrag in verband met de gezondheid en de dagdagelijkse activiteiten.

### Doelpopulatie.

De PROCOG richt zich bijzonder tot patiënten met cognitieve stoornissen.

### Beschrijving

De PROCOG is een auto-rapportage vragenlijst met 55 items. Het meet basissymptomen zoals de eigen perceptie omtrent de impact van cognitieve stoornissen op het dagelijkse leven van de patiënt. De vragen worden op een Likert schaal met vijf punten beoordeeld (van 0 (helemaal niet) tot 4 (altijd) .

Men bekomt de totaalscore door de punten van alle items op te tellen (de resultaten gaan van 0 tot 220).

De test bestaat uit zes subschalen die de items per categorie onderverdelen:

- affectief
- competentieverlies
- semantisch geheugen
- herinnering aan recente gebeurtenissen
- cognitieve functie
- sociale impact

De scores van elke subschaal worden berekend door de gemiddelde waarde van alle items van de subschaal te berekenen. Als minder dan de helft van de items van de subschaal zijn ingevuld, kunnen deze punten niet in de totaalscore worden meegeteld.

Hoge waarden duiden op een grotere ernst van de symptomen en hun invloed op het dagelijkse leven van de patiënt.

De vragenlijst moet door de patiënt worden ingevuld. Als de patiënt dat niet kan doen, kan de vragenlijst door een familielid worden ingevuld.

### Betrouwbaarheid

De betrouwbaarheid van de PROCOG wordt aangetoond door de verschillende items waaruit de schaal bestaat te correleren (*Internal Consistency*). Deze interne consistentie van de test werd voor de PROCOG beoordeeld door de Cronbach's alpha te berekenen. Die ligt voor alle subschalen rond 0,82 (Frank et al.2006).

De stabiliteit van de test (*Stability*), die gemeten wordt door de test opnieuw af te nemen (*test-retest*), werd door de inter class correlatiecoëfficiënt beoordeeld (ICC). De resultaten liggen naargelang de subschalen van de test tussen 0,49 en 0,90. Men kan zeggen dat de punten tussen de twee uitgaven van de test stabiel bleven.

### Validiteit

Klinische experts hebben het instrument onderzocht voor de indrukvaliditeit van het instrument (*Face validity*).

De psychometrische validiteit van de PROCOG is voor alle diagnostische groepen goed (MCI & DTA).

Voor alle onderwerpen werd er een correlatie aangetoond tussen de resultaten die men met de PROCOG verkreeg en die van twee andere schalen (*Concurrent Validity*). De correlatiecoëfficiënt met de QOL-AD was  $r = -0,53$  en  $r = 0,60$  met de CES-D.

De punten die er in de groep met patiënten met lichte stoornissen (MCI) werden verkregen verschillen significant van de resultaten van de groep met dementerende Alzheimer (DAT), met uitzondering van de subschaal 'sociale invloed' (*Discriminant Validity*). De resultaten van de subschaal die het langetermijngeheugen beoordeelt verschillen niet significant binnen de drie groepen. Over het algemeen onderscheidden de cognitief iintacte personen zich van de MCI of DAT patiënten.

### Andere studie

Er is geen enkele andere validiteitsstudie over de PROCOG beschikbaar in de literatuur.

### Gebruiksvriendelijkheid

Het duurt minder dan 12 minuten om de PROCOG in te vullen.

### Referenties

Frank, L., Flynn, J. A., Kleinman, L., Margolis, M. K., Matza, L. S., Beck, C., and Bowman, L. 2006. "Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment." *Int Psychogeriatr.* 18(1):135-49.

### Het meetinstrument is te vinden bij

Frank, L., Flynn, J. A., Kleinman, L., Margolis, M. K., Matza, L. S., Beck, C., and Bowman, L. 2006. "Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment." *Int Psychogeriatr.* 18(1):135-49.

## PATIENT-REPORTED OUTCOMES IN COGNITIVE IMPAIRMENT (PROCOG)

Frank L. (2006)

U.S.A. (English)

Author (year)	Setting	Sample (n)	Design	Reliability	Validity
"Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment." Frank, L., & al. (2006)	Five clinical sites across the USA	186 Subjects > 64 years (78 with mild cognitive impairment; 75 with mild dementia Alzheimer type and 33 cognitive intact)	Validation study	IC S	FV CrV

Result reliability	Result validity	Commentary
<p><b>(IC) Internal Consistency</b> Chronbach's <math>\alpha</math> : above 0.82</p> <p><b>(S) Test retest</b> ICC: ranges from 0.49 to 0.90</p>	<p><b>(FV) Face Validity</b> Clinical experts reviewed the instrument for face validity and minor revisions was submitted.</p> <p><b>(CrV) Concurrent Validity:</b> QOL-AD : <math>r = -0.53</math> CES-D <math>r = 0.6</math></p> <p><b>(CrV) Discriminant Validity</b> MCI and DAT scores differed significantly (<math>p &lt; 0.05</math>).</p>	

Reliability: Stability (S), Internal consistency (IC), Equivalence (E)

Validity: Face validity (FV), Content validity (CtV), Criterion validity (CrV), Construct validity (CsV)

Sensitivity (Sen), Specificity (Sp), Positive Predictive Value (PPV), Negative Predictive Value (NPV), Receiver Operating Curve (ROC), Likelihood Ratio (LR), Odds Ratio (OR)

Quality of life-Alzheimer's Disease (QOL-AD), Centers for Epidemiologic studies-Depression Scale (CES-D), (MCI) Mild cognitive impairment, (DAT) dementia Alzheimer

## **Patient–reported Outcomes in Cognitive Impairment (PROCOG)**

*Frank L.*

Frank, L., Flynn, J. A., Kleinman, L., Margolis, M. K., Matza, L. S., Beck, C., and Bowman, L. 2006. "Validation of a New Symptom Impact Questionnaire for Mild to Moderate Cognitive Impairment."

## Appendix A.: PROCOG – Patient Version

Date Completed: \_\_\_\_\_

Initials: \_\_\_\_\_

### PROCOG – Patient Version

Below are some questions about ways your memory affects your life. For each question, think about the ***last two weeks***. Please check the response that best describes you, where **0** is ***None of the time***, and **4** is ***All of the time***. If you are unsure about how to answer a question, please give the best answer you can.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
	0	1	2	3	4
1. How much do you rely on reminder notes, lists, or calendars?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Do you walk into a room and forget why you went there?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Do you have difficulty finding words to say what you want to say?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Does it take you longer than you would like to figure things out?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Do you get lost finding your way to places that you've been many times before?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. Do you have trouble finding things around the house?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. Do you forget where things are kept in the house (for example, where the sugar bowl belongs)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. Do you have difficulty following the meaning of things you read?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. Do you have trouble concentrating on conversations?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. Do you have trouble concentrating on what you read?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. Do you misplace things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. How often do family members or friends say you forget things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
		0	1	2	3	4
13.	Do family members or friends say you repeat the same questions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14.	Do family members or friends say you repeat the same stories or jokes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15.	Because of your memory or thinking problems, how often have you cut back on social activities outside the home?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16.	Because of your memory or thinking problems, how often have family members or friends avoided you?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17.	How often do you feel embarrassed or ashamed about your memory?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18.	Because of your memory or thinking problems, how often do you get frustrated?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19.	Because of your memory or thinking problems, how often do you get angry?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20.	Because of your memory or thinking problems, how often do you feel anxious or tense?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
21.	How often do your memory or thinking problems make you feel sad?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
22.	Because of your memory or thinking problems, how often do you feel concerned about the future?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4



Below are some more questions about ways your memory affects your life. For each question, think about the **last two weeks**. Please check the response that best describes you, where **0** is **Not at all difficult**, and **4** is **Extremely difficult**. If you are unsure about how to answer a question, please give the best answer you can.

	Not at all difficult	A little bit difficult	Somewhat difficult	Very difficult	Extremely difficult
	0	1	2	3	4
23. How difficult is remembering names of people you know well, like family or friends?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
24. ...remembering names of people you don't see often?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
25. ...remembering names of new people you meet?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
26. ...remembering names of common objects or things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
27. ...remembering what you just read?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
28. ...remembering what you just heard?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
29. How difficult is remembering your plans for each day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
30. ...remembering things that happened in the last week?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
31. ...remembering things you did yesterday?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
32. ...remembering things you did earlier in the day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
33. ...remembering what you were doing if you get interrupted?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
34. ...remembering events from years ago?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
35. How difficult is it to follow written instructions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
36. How difficult is it to follow spoken instructions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below are some more questions about ways your memory affects your life. For each question, think about the ***last two weeks***. Please check the response that best describes you, where **0** is ***NO, not at all***, and **4** is ***YES, completely***. If you are unsure about how to answer a question, please give the best answer you can.

		NO, not at all	A little bit	Somewhat	Very much	YES, completely
		0	1	2	3	4
37.	Do you get annoyed at yourself because of your memory or thinking problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38.	Do you feel embarrassed because of forgetting things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39.	Because of your memory or thinking problems, do you feel less confident in yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40.	Because of your memory or thinking problems, do you feel you are less effective or successful in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41.	Because of your memory or thinking problems, have you cut back on your usual hobbies or activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42.	Is your thinking fuzzy or not sharp?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43.	Do you try to hide your memory or thinking problems from others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44.	Because of your memory or thinking problems, have you stopped doing things you used to enjoy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45.	Because of your memory or thinking problems, are there hobbies or activities you don't do as well as you once could?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46.	Because of your memory or thinking problems, do you find you don't perform household chores as well as you once did (for example, preparing dinner, fixing things around the house)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	NO, not at all	A little bit	Somewhat	Very much	YES, completely
	0	1	2	3	4
47. Because of your memory or thinking problems, do you find you don't perform activities as well as you once did (for example, playing cards, working at the computer)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
48. Because of your memory or thinking problems, is it more difficult to write or do activities with your hands now?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
49. Do you think friends call you less than they used to because of your memory or thinking problems?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
50. Because of your memory or thinking problems, have family routines changed, like who does most of the driving or cooking or who usually handles finances?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below are some more questions about ways your memory affects your life. For each question, think about the **last two weeks**. Please check the response that best describes you, where **0** is **Not at all**, and **4** is **A great deal**. If you are unsure about how to answer a question, please give the best answer you can.

	Not at all	A little bit	Somewhat	Very much	A great deal
	0	1	2	3	4
51. Do friends or family members say you are more irritable now than before?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
52. Do your memory or thinking problems add to your stress level?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
53. Because of your memory or thinking problems, do you find it more difficult to decide what to wear than it used to be?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
54. Because of your memory or thinking problems, how often have you cut back on seeing friends?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
55. Because of your memory or thinking problems, do you make more mistakes with money now (for example, when balancing the checkbook or making change)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Thank you for completing this questionnaire.

# June 2005 **PROCOG – Informant Version**

The PROCOG is a 55-item self-administered questionnaire designed to measure a range of patient reported outcomes unique to individuals with cognitive impairment of mild to moderate severity. It was designed to be suitable for individuals with mild cognitive impairment as well as Dementia of the Alzheimer's Type. There is a patient version and an informant version. The informant version is for completion by an informant familiar with the individual with cognitive impairment. This instrument was designed to be completed independently by the respondent. It is recommended that the informant be familiar with the individual on an ongoing basis, with a minimum of in-person interaction of once per week. We recommend collection of information about the informant's relationship to patient (e.g., spouse, adult child, friend).

**Scoring:** Questions are rated on a 4-point Likert scale, with a total of 4 different response scales (e.g., *none of the time* to *all of the time*; *not at all* to *a great deal*). Higher values indicate greater severity of symptoms and their impact. A total score is computed as the sum of all items (score range: 0-220). Subscale scores are calculated as the mean value of all items within the subscale for multi-item subscales, and as the item value for the single-item Long Term Memory subscale (score range 0-4).

**Subscales:** There are 7 subscales:

- Affect (items 17, 18, 19, 20, 21, 22, 37, 38, 39, 40, 52),
- Skill Loss (items 35, 36, 41, 43, 45, 46, 47, 48, 50, 53, 55),
- Semantic Memory (items 2, 23, 24, 25, 26),
- Memory for Recent Events (items 2, 27, 28, 29, 30, 31, 32, 33),
- Cognitive Functioning (items 1, 4, 5, 6, 7, 8, 9, 10, 11, 42),
- Social Impact (items 12, 13, 14, 15, 16, 44, 49, 51, 54), and
- Long Term Memory (item 34).

An individual subscale score is set to missing if >50% of items within that subscale are missing. A total score is calculated only if >50% of items have non-missing data.

**Contact Information:** For further information please contact:

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Voice: 301 986 6762 FAX: 301 654 9864 E-mail: [Lori.Frank@unitedbiosource.com](mailto:Lori.Frank@unitedbiosource.com) Date Completed: \_\_\_\_\_ Initials: \_\_\_\_\_

### **PROCOG – Informant Version**

Below are some questions about ways the memory of the study participant affects his/her life. For each question, think about the **last two weeks**. Please check the response that best describes the person, where **0** is ***None of the time***, and **4** is ***All of the time***. If you are unsure about how to answer a question, please give the best answer you can.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
	0	1	2	3	4
1. How much does the person rely on reminder notes, lists, or calendars?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Does the person walk into a room and forget why he/she went there?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Does the person have difficulty finding words to say what he/she wanted to say?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Does it take the person longer than he/she would like to figure things out?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Does the person get lost finding his/her way to places that he/she has been many times before?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. Does the person have trouble finding things around the house?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. Does the person forget where things are kept in the house (for example, where the sugar bowl belongs)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. Does the person have difficulty following the meaning of things he/she reads?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. Does the person have trouble concentrating on conversations?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. Does the person have trouble concentrating on what he/she reads?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. Does the person misplace things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. How often do family members or friends say the person forgets things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. Do family members or friends say the person repeats the same questions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

  

None of the time	A little of the time	Some of the time	Most of the time	All of the time
0	1	2	3	4

- |     |   |                               |                               |                               |                               |                               |
|-----|---|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|
| 14. | Do family members or friends say the person repeats the same stories or jokes?  | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 15. | Because of the person's memory or thinking problems, how often has the person cut back on social activities outside the home? | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 16. | Because of the person's memory or thinking problems, how often have family members or friends avoided the person?             | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 17. | How often does the person feel embarrassed or ashamed about his/her memory?   | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 18. | Because of the person's memory or thinking problems, how often does he/she get frustrated?                                    | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 19. | Because of the person's memory or thinking problems, how often does he/she get angry?   | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 20. | Because of the person's memory or thinking problems, how often does he/she feel anxious or tense?                             | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 21. | How often do the person's memory or thinking problems make him/her feel sad?  | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |
| 22. | Because of the person's memory or thinking problems, how often does he/she feel concerned about the future?                   | <input type="checkbox"/><br>0 | <input type="checkbox"/><br>1 | <input type="checkbox"/><br>2 | <input type="checkbox"/><br>3 | <input type="checkbox"/><br>4 |

Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the ***last two weeks***. Please check the response that best describes the person, where **0** is ***Not at all difficult***, and **4** is ***Extremely difficult***. If you are unsure about how to answer a question, please give the best answer you can.

	Not at all difficult	A little bit difficult	Somewhat difficult	Very difficult	Extremely difficult
	0	1	2	3	4
23. How difficult does the person find remembering names of people he/she knows well, like family or friends?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
24. ...remembering names of people he/she doesn't see often?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
25. ...remembering names of new people he/she meets?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
26. ...remembering names of common objects or things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
27. ...remembering what he/she just read?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
28. ...remembering what he/she just heard?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
29. How difficult does the person find remembering his/her plans for each day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
30. ...remembering things that happened in the last week?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
31. ...remembering things he/she did yesterday?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
32. ...remembering things he/she did earlier in the day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
33. ...remembering what he/she was doing if he/she got interrupted?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
34. ...remembering events from years ago?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
35. How difficult does the person find following written instructions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
36. How difficult does the person find following spoken instructions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4



Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the **last two weeks**. Please check the response that best describes the person, where **0** is **NO, not at all**, and **4** is **YES, completely**. If you are unsure about how to answer a question, please give the best answer you can.

	NO, not at all	A little bit	Somewhat	Very much	YES, completely
	0	1	2	3	4
37. Does the person get annoyed at him- or herself because of his/her memory or thinking problems?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
38. Does the person feel embarrassed because of forgetting things?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
39. Because of the person's memory or thinking problems, does he/she feel less confident in him- or herself?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
40. Because of the person's memory or thinking problems, does he/she feel that he/she is less effective or successful in his/her life?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
41. Because of the person's memory or thinking problems, has he/she cut back on his/her usual hobbies or activities?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
42. Is the person's thinking fuzzy or not sharp?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
43. Does the person try to hide his/her memory or thinking problems from others?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
44. Because of the person's memory or thinking problems, has he/she stopped doing things he/she used to enjoy?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

	NO, not at all	A little bit	Somewhat	Very much	YES, completely
	0	1	2	3	4
45. Because of the person's memory or thinking problems, are there hobbies or activities he/she doesn't do as well as he/she once could?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
46. Because of the person's memory or thinking problems, does he/she find that he/she doesn't perform household chores as well as he/she once did (for example, preparing dinner, fixing things around the house)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
47. Because of the person's memory or thinking problems, does he/she find that he/she doesn't perform activities as well as he/she once did (for example, playing cards, working at the computer)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
48. Because of the person's memory or thinking problems, does he/she find it more difficult to write or do activities with his/her hands now?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
49. Does the person think friends call him/her less than they used to because of his/her memory or thinking problems?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
50. Because of the person's memory or thinking problems, have family routines changed, like who does most of the driving or cooking or who usually handles finances?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the ***last two weeks***. Please check the response that best describes the person, where **0** is ***Not at all***, and **4** is ***A great deal***. If you are unsure about how to answer a question, please give the best answer you can.

	Not at all	A little bit	Somewhat	Very much	A great deal
	0	1	2	3	4
51. Do friends or family members say the person is more irritable now than before?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
52. Do the person's memory or thinking problems add to his/her stress level?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
53. Because of the person's memory or thinking problems, does he/she find it more difficult to decide what to wear than it used to be?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
54. Because of the person's memory or thinking problems, how often has he/she cut back on seeing friends?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
55. Because of the person's memory or thinking problems, does he/she make more mistakes with money now (for example, when balancing the checkbook or making change)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

### Wat is BEST?

BEST staat voor BELgian Screening Tools en is een studie uitgevoerd door de Universiteit Gent, afdeling Verplegingswetenschap in opdracht van de Federale Overheidsdienst Volksgezondheid, Veiligheid van de voedselketen en Leefmilieu, en in samenwerking met de Université Catholique de Louvain.

### Doel van BeST

Bedoeling van het project is het oprichten van een databank met wetenschappelijk gevalideerde meetinstrumenten. Met het oog op het objectiveren van de diagnostiek en van de resultaten van verpleegkundige interventies, zijn valide en betrouwbare meetinstrumenten een basisvoorwaarde om effectieve verpleegkundige zorg te kunnen bieden. Onze aandacht gaat uit naar meetinstrumenten voor de verpleegkundige interventies die bij de Minimale Verpleegkundige Gegevens gescoord worden.

### Wat kan u vinden in dit rapport?

In dit rapport wordt de inhoud van het project alsook de gehanteerde methodologie beschreven. Vervolgens worden de verschillende meetinstrumenten per thema besproken. Bovendien wordt het instrument ter beschikking gesteld indien we hiertoe toestemming verkregen. Meetinstrumenten met een hoge betrouwbaarheid en validiteit werden tevens naar het Nederlands en het Frans vertaald.

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Gelieve bij elk gebruik van dit rapport als volgt te refereren:

Daem, M., Piron, C., Lardennois, M., Gobert, M., Folens, B., Vanderwee, K., Grypdonck, M., & Defloor T. (2007). Opzetten van een databank met gevalideerde meetinstrumenten: BEST-project. Brussel, Federale Overheidsdienst Volksgezondheid, Veiligheid van de voedselketen en Leefmilieu.