Patient-reported Outcomes in Cognitive Impairement (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 <u>last two weeks</u>. 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?	0		Ď		4
2.	Do you walk into a room and forget why you went there?	0				4
3.	Do you have difficulty finding words to say what you want to say?	0				4
4.	Does it take you longer than you would like to figure things out?	0			3	4
5.	Do you get lost finding your way to places that you've been many times before?	Ö		<u></u>		4
6.	Do you have trouble finding things around the house?	0			i a	4
7.	Do you forget where things are kept in the house (for example, where the sugar bowl belongs)?	0				4
8.	Do you have difficulty following the meaning of things you read?		1		3	4
9.	Do you have trouble concentrating on conversations?	<u></u>		Ö		4
10.	Do you have trouble concentrating on what you read?	0			3	
11.	Do you misplace things?			2	3	4
12.	How often do family members or friends say you forget things?	0			3	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?	0				4
14.	Do family members or friends say you repeat the same stories or jokes?	0		, s	a	4
15.	Because of your memory or thinking problems, how often have you cut back on social activities outside the home?	0				4
16.	Because of your memory or thinking problems, how often have family members or friends avoided you?				☐ 3	4
17.	How often do you feel embarrassed or ashamed about your memory?	0	P			4
18.	Because of your memory or thinking problems, how often do you get frustrated?				3	4
19.	Because of your memory or thinking problems, how often do you get angry?	0	1		3	4
20.	Because of your memory or thinking problems, how often do you feel anxious or tense?	0			3	4
21.	How often do your memory or thinking problems make you feel sad?			, ,		4
22.	Because of your memory or thinking problems, how often do you feel concerned about the future?	0				☐ 4

Below are some more questions about ways your memory affects your life. For each question, think about the <u>last two weeks</u>. 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?	0	P	2	3	4
24.	remembering names of people you don't see often?		1	2	3	4
25.	remembering names of new people you meet?	0		2	3	4
26.	remembering names of common objects or things?		1	2	3	□ •
27.	remembering what you just read?	0	1	2	3	4
28.	remembering what you just heard?	0	1	2	3	4
29.	How difficult is remembering your plans for each day?	Ö	1		3	4
30.	remembering things that happened in the last week?	0		2	3	
31.	remembering things you did yesterday?	Ö			3	
32.	remembering things you did earlier in the day?		Image: section of the content of the	2	3	4
33.	remembering what you were doing if you get interrupted?	0	Image: Control of the		3	
34.	remembering events from years ago?	0		2	3	4
35.	How difficult is it to follow written instructions?				3	□ +
36.	How difficult is it to follow spoken instructions?	Ö		2	3	□ 4

Below are some more questions about ways your memory affects your life. For each question, think about the <u>last two weeks</u>. 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 2	Very much	YES, completely 4
37.	Do you get annoyed at yourself because of your memory or thinking problems?	0	Image: section of the content of the		3	
38.	Do you feel embarrassed because of forgetting things?		P			
39.	Because of your memory or thinking problems, do you feel less confident in yourself?	0			3	☐ 4
40.	Because of your memory or thinking problems, do you feel you are less effective or successful in your life?		P			
41.	Because of your memory or thinking problems, have you cut back on your usual hobbies or activities?	0			3	□ 4
42.	Is your thinking fuzzy or not sharp?				3	. □ .
43.	Do you try to hide your memory or thinking problems from others?		D.		3	□ 4
44.	Because of your memory or thinking problems, have you stopped doing things you used to enjoy?	 0			3	
45.	Because of your memory or thinking problems, are there hobbies or activities you don't do as well as you once could?			2	3	4
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)?		P		3	4

		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)?		P	-	3	4
48.	Because of your memory or thinking problems, is it more difficult to write or do activities with your hands now?				3	4
49.	Do you think friends call you less than they used to because of your memory or thinking problems?	0	P		3	
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?	0	Ŗ		3	

Below are some more questions about ways your memory affects your life. For each question, think about the <u>last two weeks</u>. 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 0	A little bit 1	Somewhat 2	Very much 3	A great deal 4
51.	Do friends or family members say you are more irritable now than before?		1			4
52.	Do your memory or thinking problems add to your stress level?	Ö	1		3	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?		1	2	٦	4
54.	Because of your memory or thinking problems, how often have you cut back on seeing friends?	Ö		<u>_</u>		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)?	0			3	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:

Lori Frank, PhD Center for Health Outcomes Research, United BioSource Corporation 7101 Wisconsin Avenue, Suite 600

Bethesda, MD 20814

Voice: 301 986 6762 FAX	301 654 9864 E-mail: 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 <u>last two weeks</u>. 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	A little of	Some of	Most of	All of
		the time 0	the time 1	the time 2	the time 3	the time 4
1.	How much does the person rely on reminder notes, lists, or calendars?		1	2	3	4
2.	Does the person walk into a room and forget why he/she went there?	0	1	2	3	4
3.	Does the person have difficulty finding words to say what he/she wanted to say?	0	1	2	3	4
4.	Does it take the person longer than he/she would like to figure things out?	0	1	2	3	4
5.	Does the person get lost finding his/her way to places that he/she has been many times before?	0	1	2	3	4
6.	Does the person have trouble finding things around the house?	0	1	2	3	4
7.	Does the person forget where things are kept in the house (for example, where the sugar bowl belongs)?	0	1	2	3	4
8.	Does the person have difficulty following the meaning of things he/she reads?	0	1	2	3	4
9.	Does the person have trouble concentrating on conversations?	0	1	2	3	4
10.	Does the person have trouble concentrating on what he/she reads?	0	1		3	4
11.	Does the person misplace things?	0	1	2	3	4
12.	How often do family members or friends say the person forgets things?	0	1	2	3	4
13.	Do family members or friends say the person repeats the same questions?	0	1	2	3	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?		1	2	3	4
15.	Because of the person's memory or thinking problems, how often has the person cut back on social activities outside the home?	0	1	2	3	4
16.	Because of the person's memory or thinking problems, how often have family members or friends avoided the person?	0	1	2	3	4
17.	How often does the person feel embarrassed or ashamed about his/her memory?	0	1	2	3	4
18.	Because of the person's memory or thinking problems, how often does he/she get frustrated?	0	1	2	3	4
19.	Because of the person's memory or thinking problems, how often does he/she get angry?	0		2	3	4
20.	Because of the person's memory or thinking problems, how often does he/she feel anxious or tense?	0	1	2	3	4
21.	How often do the person's memory or thinking problems make him/her feel sad?	0	1	2	3	4
22.	Because of the person's memory or thinking problems, how often does he/she feel concerned about the future?	0	1	2	3	4

Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the <u>last two weeks</u>. 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?	0	1	2	3	4
24.	remembering names of people he/she doesn't see often?	0	1	2	3	4
25.	remembering names of new people he/she meets?	0	1	2	3	4
26.	remembering names of common objects or things?	0	1	2	3	4
27.	remembering what he/she just read?	0	1	2	3	4
28.	remembering what he/she just heard?	0	1	2	3	4
29.	How difficult does the person find remembering his/her plans for each day?	0	1	2	3	4
30.	remembering things that happened in the last week?	0	1	2	3	4
31.	remembering things he/she did yesterday?	0	1	2	3	4
32.	remembering things he/she did earlier in the day?	0	1	2	3	4
33.	remembering what he/she was doing if he/she got interrupted?		1	2	3	4
34.	remembering events from years ago?	0	1	2	3	4
35.	How difficult does the person find following written instructions?	0	1	2	3	4
36.	How difficult does the person find following spoken instructions?	0	1	2	3	4

Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the <u>last two weeks</u>. 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?	0	1	2	3	4
38.	Does the person feel embarrassed because of forgetting things?	0	1	2	3	4
39.	Because of the person's memory or thinking problems, does he/she feel less confident in him- or herself?	0		2	3	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?	0	1	2	3	4
41.	Because of the person's memory or thinking problems, has he/she cut back on his/her usual hobbies or activities?		1	2	3	4
42.	Is the person's thinking fuzzy or not sharp?	0	1	2	3	4
43.	Does the person try to hide his/her memory or thinking problems from others?	0	1	2	3	4
44.	Because of the person's memory or thinking problems, has he/she stopped doing things he/she used to enjoy?	0	1	2	3	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?				- 3	
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)?	0	1	2	3	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)?	0	1	2	3	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?	0	1	2	3	4
49.	Does the person think friends call him/her less than they used to because of his/her memory or thinking problems?	0	1	2	3	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?	0	1	2	3	4

Below are some more questions about ways the study participant's memory affects his/her life. For each question, think about the <u>last two weeks</u>. 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?	0	1	2	3	4
52.	Do the person's memory or thinking problems add to his/her stress level?	0	1	2	3	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?	0	<u> </u>	2	3	4
54.	Because of the person's memory or thinking problems, how often has he/she cut back on seeing friends?	0	1	2	3	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)?	0	1	2	3	4