



**UNIKLINIK
KÖLN**

Zentrum für
Palliativmedizin



**UNIKLINIK
KÖLN**

Klinik und Poliklinik
für Neurologie

Compliance form for participation in the study „**Communication, Coordination und Security for People with Multiple Sclerosis (COCOS-MS)**“

Patient ID:

Date: - -
D D M M Y Y Y Y

Assessment (please encircle)	1 (Baseline)	2	3	4	5	6 (Follow-Up)
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Questions need to be answered in order, unless indicated otherwise.

Characteristics of assessment

	yes	no	partially
1) Questionnaires were completed by the patient themselves (self assessment).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HALEMS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• IPOS (Neuro-S8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HADS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Cost booklet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Risk perception	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HOPE+ (Baseline assessment only)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes , then continue to question 11)			
2) Patient filled in questionnaire with the help of another person (e.g. formal / informal caregiver) (joint assessment).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HALEMS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• IPOS (Neuro-S8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HADS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Cost booklet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Risk perception	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• HOPE+ (Baseline assessment only)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes , then continue to question 11)			
3) Another person (e.g. formal / informal caregiver) filled in questionnaires on behalf of the patient (proxy assessment).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If no , then continue to question 7)			

- | | | | |
|------------------------------------|-----------------------|-----------------------|-----------------------|
| • HALEMS | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| • IPOS (Neuro-S8) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| • HADS | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| • Cost booklet | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| • Risk perception | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| • HOPE+ (Baseline assessment only) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Reasons for proxy assessment

- | | yes | no |
|--|-----------------------|-----------------------|
| 4) Patient was too ill (incapacitated by the disease itself or related limitations / complications). | <input type="radio"/> | <input type="radio"/> |
| 5) It was not possible to make an appointment / meet with the patient. | <input type="radio"/> | <input type="radio"/> |
| 6) Patient declined. Please specify reasons: | <input type="radio"/> | <input type="radio"/> |
| a) felt too ill | <input type="radio"/> | <input type="radio"/> |
| b) felt overburdened | <input type="radio"/> | <input type="radio"/> |
| c) lack of time | <input type="radio"/> | <input type="radio"/> |
| d) lack of interest | <input type="radio"/> | <input type="radio"/> |
| e) felt bothered by questions | <input type="radio"/> | <input type="radio"/> |
| f) other reasons, please specify: | <input type="radio"/> | <input type="radio"/> |
| | | |

Please continue to question 11)

Reasons why proxy assessment was not possible

- | | yes | no |
|--|-----------------------|-----------------------|
| 7) No such person available. | <input type="radio"/> | <input type="radio"/> |
| 8) Person declined. Please specify reasons: | <input type="radio"/> | <input type="radio"/> |
| a) did not feel competent enough to fill in questionnaire on behalf of the patient | <input type="radio"/> | <input type="radio"/> |
| b) felt overburdened | <input type="radio"/> | <input type="radio"/> |
| c) lack of time | <input type="radio"/> | <input type="radio"/> |
| d) lack of interest | <input type="radio"/> | <input type="radio"/> |
| e) felt bothered by questions | <input type="radio"/> | <input type="radio"/> |
| f) other reasons, please specify: | <input type="radio"/> | <input type="radio"/> |
| | | |

- 9) Patient died.
- If yes,
- Date: - -
D D M M Y Y Y Y
- Place of death:
- a) clinic / hospital
- b) at home
- c) nursing home
- d) hospice
- e) short-term nursing
- f) assisted living
- g) elsewhere, please specify:
-

- 10) Consent to participate in study was withdrawn.

Place of assessment

- | | yes | no |
|------------------------------------|-----------------------|-----------------------|
| 11) Patient's home | <input type="radio"/> | <input type="radio"/> |
| 12) Caregiver's home | <input type="radio"/> | <input type="radio"/> |
| 13) Patient's and caregiver's home | <input type="radio"/> | <input type="radio"/> |
| 14) Clinic / hospital | <input type="radio"/> | <input type="radio"/> |
| 15) Nursing home | <input type="radio"/> | <input type="radio"/> |
| 16) Hospice | <input type="radio"/> | <input type="radio"/> |
| 17) Short-term nursing | <input type="radio"/> | <input type="radio"/> |

18) Assisted living

19) Elsewhere, please specify:

Time of assessment

yes no

20) Questionnaires were completed within the planned time frame.
If **no**, please specify reasons:

.....

.....

Completeness

yes no

21) Were all questions answered?
If **no**, please specify reasons:

.....

.....

Blinding

yes no

22) Blinding of the outcome assessor is still given.
If **no**, please specify reasons:

.....

.....



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Compliance form for participation in the study „Communication, Coordination und Security for People with Multiple Sclerosis (COCOS-MS)“

Caregiver ID:

Date: / - / - / / /

Assessment <small>(please encircle)</small>	1 <small>(Baseline)</small>	2	3	4	5	6 <small>(Follow-Up)</small>
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Questions need to be answered in order, unless indicated otherwise.

Conduction of assessment

	yes	no	partially
1) Questionnaires were completed by caregiver.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> • ZBI-12 • SF-12 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes , then continue to question 5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Consent to participate in study was withdrawn:			
a) from caregiver	<input type="radio"/>	<input type="radio"/>	
b) from patient who is also participating in the study	<input type="radio"/>	<input type="radio"/>	
3) It was not possible to make an appointment / meet with the caregiver.	<input type="radio"/>	<input type="radio"/>	
4) Caregiver declined. Please specify reasons:	<input type="radio"/>	<input type="radio"/>	
a) was sick	<input type="radio"/>	<input type="radio"/>	
b) felt overburdened	<input type="radio"/>	<input type="radio"/>	
c) lack of time	<input type="radio"/>	<input type="radio"/>	
d) lack of interest	<input type="radio"/>	<input type="radio"/>	
e) felt bothered by questions	<input type="radio"/>	<input type="radio"/>	
f) other reasons, please specify:	<input type="radio"/>	<input type="radio"/>	
.....			

Place of assessment		
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		yes	no
5)	Patient's home	<input type="radio"/>	<input type="radio"/>
6)	Caregiver's home	<input type="radio"/>	<input type="radio"/>
7)	Patient's and caregiver's home	<input type="radio"/>	<input type="radio"/>
8)	Clinic / hospital	<input type="radio"/>	<input type="radio"/>
9)	Nursing home	<input type="radio"/>	<input type="radio"/>
10)	Hospice	<input type="radio"/>	<input type="radio"/>
11)	Respite care	<input type="radio"/>	<input type="radio"/>
12)	Assisted living	<input type="radio"/>	<input type="radio"/>
13)	Elsewhere, please specify:	<input type="radio"/>	<input type="radio"/>

Time of assessment		
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		yes	no
14)	Questionnaires were completed within the planned time frame. If no , please specify reasons:	<input type="radio"/>	<input type="radio"/>
		
		

Completeness

	yes	no
15) Were all questions answered? If no , please specify reasons:	<input type="radio"/>	<input type="radio"/>
.....		
.....		

Blinding

	yes	no
16) Blinding of the outcome assessor is still given. If no , please specify reasons:	<input type="radio"/>	<input type="radio"/>
.....		
.....		