



**UNIKLINIK
KÖLN**

Zentrum für
Palliativmedizin



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Klinik und Poliklinik
für Neurologie

Questionnaire on immunotherapy and risk perception for the study „**Communication, Coordination and Security for people with Multiple Sclerosis (COCOS-MS)**“

Clinical Global Impression – Change of state

1. Compared to the situation three months ago (for follow-up assessments: to the last data collection three months ago) how would you describe your general health situation (e.g., physical impairment, symptoms, emotional experience)?

- much better
 better
 somewhat better
 unchanged
 somewhat worse
 worse
 much worse
 no statement possible

Questions about your personal treatment decision on your current MS medication

2. Are you currently being treated with any of the following medications? If so, since when?

- Natalizumab (Tysabri®) since: __. __. ____
 Fingolimod (Gilenya®) since: __. __. ____
 Siponimod (Mayzent®) since: __. __. ____
 Ozanimod (Zeposia®) since: __. __. ____
 Alemtzumab (Lemtrada®) since: __. __. ____
 Ocrelizumab (Ocrevus®) since: __. __. ____
 Rituximab (MabThera®) since: __. __. ____
 Ofatumumab (Arzerra®) since: __. __. ____
 Cladribine (Mavenclad®) since: __. __. ____
 another, please specify:
 none; please specify reason, if applicable:

3. How well informed do you feel about the medication?

- very good
 good
 rather good
 rather poor
 poor
 very poor
 no statement possible

4. Which aspects were important for the selection of the current medication (multiple answers possible)? (answer only if you are currently being treated with one of the MS medications mentioned above)

- Other medications did not help.
 The current medication is the most effective.
 I was in a hopeless situation.
 There were no alternatives.
 I was willing to take the risk.
 I'm not afraid of complications.

Immunotherapy and risk perception_V01_0

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- The spectrum of side effects sounded best to me.
 It was my doctor's decision.
 other, please specify reasons:

Autonomy preferences

5. When you are faced with a decision about a MEDICAL TREATMENT IN GENERAL (examination or treatment), who should decide?

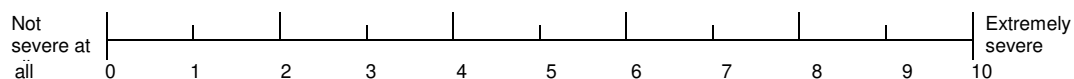
- I would like to make the decision by myself.
 I would like to make the final decision by myself but consult with the doctor.
 I would like to make the decision together with the doctor.
 The doctor should make the final decision but consult with me.
 The doctor should make the decision by himself.

6. If you have to decide whether to continue or discontinue taking medications, who should decide?

- I would like to make the decision by myself.
 I would like to make the final decision by myself but consult with the doctor.
 I would like to make the decision together with the doctor.
 The doctor should make the final decision but consult with me.
 The doctor should make the decision by himself.

Autonomy preferences on risk perception (please mark on the lines below) (cf. Boeije & Janssens 2004, Heesen et al., 2010)

7. How severe do you think your MS disease is? (cf. Heesen et al., 2010)



8. How serious do you think your MS disease is? (cf. Boeije & Janssens 2004)



9. What would a wheelchair dependency mean to you? (cf. Boeije & Janssens 2004)

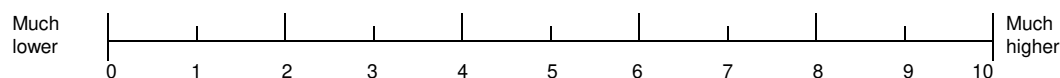


Questions on risk perception (cf. Heesen et al., 2010)

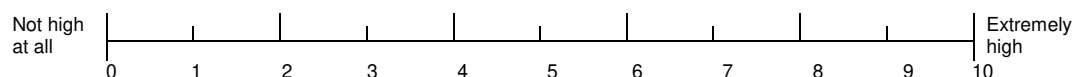
10. How would you assess the risk that your current MS therapy will result in a severe complication?



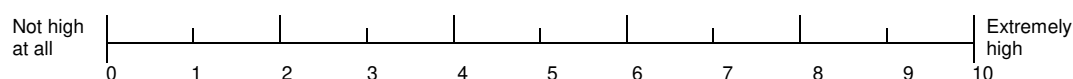
11. Given your medical history of MS and taking into account how you deal with risks in general: do you consider your PERSONAL risk of a severe complication to be lower or higher compared to other patients in the same situation?



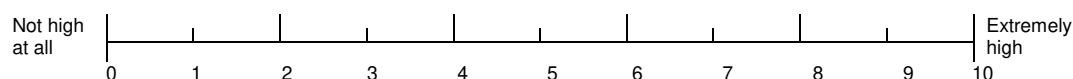
12. How do you assess the risk of developing a severe infection?



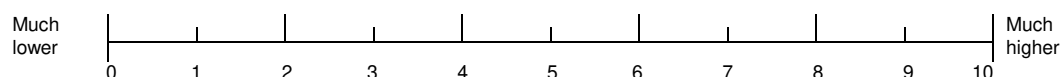
12a. How do you assess the risk of developing a corona infection with a severe course?



12b. How do you assess the risk of developing a severe viral infection of the brain called progressive multifocal leukoencephalopathy (PML)?



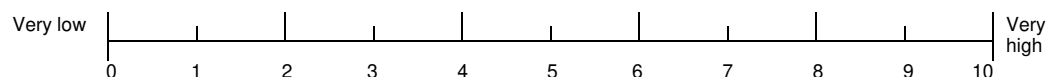
13. Given your medical history of MS and taking into account how you deal with risks in general: do you consider your PERSONAL risk of a PML to be lower or higher compared to other patients in the same situation?



14. How would you estimate the benefits of your current MS therapy?

- very high
- high
- rather high
- rather low
- low
- very low
- no statement possible

15. At what risk of complications would you continue the therapy nevertheless?



16. At what risk of complications would you discontinue the therapy?

