

**Supplementary table 1. Interview schedule**

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**Part A. Open-ended questions**

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1. If you think about your body, what functional problems do you have?
  2. In which parts of your body do you have problems?
  3. If you think about your daily life, what are your problems?
  4. If you think about your environment, factors in your surroundings, and your living conditions, what do you find
    - a. helpful or supportive?
    - b. obstructive and hindering?
  5. Which personal factors play a role in how you cope with your disease in daily life?
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**Part B. Questionnaire/instrument-based questions**

*Six currently used PROMs will be presented to the participants.*

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6. Please take some time to brainstorm on what you would like to have assessed / being asked at every clinical encounter.
  7. Please now look at the questionnaires and instruments which are used in clinical practice.
  8. What is missing?
  9. What could be left out?
  10. Do you have any other suggestions for improvement?
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*Note. For using the questions in Austria, Croatia, Italy and the Netherlands, the interview questions were translated from English into the local languages and translated back to English, blinded for the original wording of the questions, by members of the research team using a forward-backward approach <sup>16</sup>.*