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Table 3 Interview Topic Guide

INFORMATION AREA	QUESTIONS & PROMPTS
<b>Introduction to the diagnosis</b>	<ul style="list-style-type: none"> <li>- Understanding MS: First MS symptoms; first relapse; first contact with medics</li> <li>- Were you diagnosed with MS straight away or were you diagnosed with something else in the very beginning? Date of diagnosis</li> <li>- What were your first thoughts when you found out that it was MS? Did you know anything about MS before you were diagnosed?</li> <li>- What do you know about MS now? How did you find out/ learn about MS?</li> <li>- What did your clinician tell you about MS?</li> <li>- How do you feel as a person, as you about having MS?</li> </ul>
<b>Introduction to treatment</b>	<ul style="list-style-type: none"> <li>- Could you please tell me about your first chat with the clinician about the treatment? Did you initiate the prescription or was or your clinician's idea?</li> <li>- How were available treatments explained to you? Which aspects of the available medication did you discuss?</li> <li>- What were your first thoughts when you heard all this information?</li> <li>- What was the most important/scary/ relieving for you? Was this information enough for you? Was it easy to understand?</li> <li>- Were you suggested with a specific treatment or were you advised to choose?</li> <li>- Did you make the decision immediately or you decided/ had to wait? Why?</li> <li>- At what point did this discussion happen? Immediately after the diagnosis? After how many appointments?</li> <li>- Very often MS nurse is closely involved in treatment introduction and selection. Was this the case in your experience? How did you find this experience?</li> <li>- How did you find the decision making process? Was it easy to decide?</li> </ul>
<b>DMT characteristics and decision making</b>	<ul style="list-style-type: none"> <li>- You are currently considering a possibility to start or have recently decided to start treatment. What factors are the most important for you in making this decision? Why these particular factors?</li> <li>- How much information did you have about the way the treatment works and its benefits? What were your first thought when you found out about it? Did your position or feeling about it change? How?</li> <li>- When it comes to the effect of or the way DMTs work, it is usually making relapses milder or less frequent and slowing down illness progression in the future. What is more important for you at this stage?</li> <li>- How do you think, may your priorities change in the future?</li> <li>- Some people have relapses even though they are on treatment. How do you think, what would be your position if this happens to you?</li> <li>- How would you describe an effective treatment?</li> <li>- How much information did you have about side effects and risks of your treatment? Where did you get this information from? What were your thoughts when you found out all this? How did this effect your decision?</li> <li>- The majority of treatments have various side effects. What about your chosen treatment?</li> <li>- What kind of side effects would you be willing and able to tolerate and to which would you say 'No'?</li> <li>- Some treatments may cause additional illnesses like liver-dysfunction, kidney problems, thyroids and others. What is your take on this? As you may know, some treatments may cause severe side effects like blood cloth or even death. Would you be willing to take risk and choose such kind of treatment if it would slow down illness progression or decrease the number of relapses? How far</li> </ul>

	<p>would you go? If you need to choose what would you choose: more effective treatment that has more side effects or less effective treatment that has less side effects?</p> <ul style="list-style-type: none"> <li>- Do/ did you explore treatment options yourself? Where did you look for information? Does this kind of information impact your choice? How?</li> <li>- As you know, DMTs are mainly in three forms: tablets, self-injections and infusions in hospital. Which mode of administration would you prefer? If you need to choose, what would you choose: less effective treatment that is in your preferred mode of administration or more effective treatment that is in a format that you do not like?</li> <li>- Some DMTs require regular monitoring, like having your blood tested, meaning that every 3, 6 or 12 months you may need to go to the hospital for a check-up. Would this have an impact on which medication you choose?</li> <li>- What are your priorities or preferences for the treatment? What would be your top 3 priorities for a DMT? How would you describe a realistically ideal DMT?</li> </ul>
<p><b>Interaction with a clinicians and decision making</b></p>	<ul style="list-style-type: none"> <li>- Did you discuss the things we have just discussed with your clinician? Did your priorities and positions match? If no, how did you deal with the situation?</li> <li>- If the neurologist advised you to start/ not start/ delay treatment, what reasons did he/ she provide? Have you changed the consultant or sought further medical advice to gain access to a specific DMT?</li> <li>- How do you think, the way that you clinician explain treatment options may influence your selection of DMT?</li> <li>- How would you describe communication experience with your clinician in general? Did you have any questions/ concerns about DMT before you have started treatment? How were they addressed? Did you have enough time and attention to discuss things that matter to you?</li> <li>- What staff characteristics are important, in your opinion, when they interact with the MS patient who is deciding treatments? Some people say that often clinicians see illness and only then a person. What about your case? Were your personal life circumstances discussed and considered when deciding treatment?</li> <li>- What was your experience when communicating with MS nurse? When did you meet MS nurse? What did you discuss with her/ him? How was communication with MS nurse different from communication with a clinician? Did you find it helpful in terms of deciding which treatment to choose? What in particular was helpful?</li> </ul>
<p><b>Social support and decision making</b></p>	<ul style="list-style-type: none"> <li>- Do your family members, friends or colleagues know about your MS?</li> <li>- Is anyone from your family or close environment involved in the decision making process? How significant is their participation and support? Do your and their positions match?</li> </ul>
<p><b>General</b></p>	<ul style="list-style-type: none"> <li>- How would you describe your attitude to treatment decisions in general? Do you prefer to make decisions with full consultation with family/ friends or make decisions on your own? Would you take any alternative or additional treatments if needed?</li> <li>- How would you describe your life before and after the diagnosis? What have been the main changes? Has anything else changed? How do you manage the changes? Do you do anything to keep your life as it was before the diagnosis? What are your life goals: 1 year; 5 years; 10 years? How do you think, does having MS may reshape these plans? If yes, how?</li> </ul>