Appendix 1 Questions included in the neurologists’ questionnaire

1. On average, how long following the diagnosis of MS do you usually start to actively treat a patient with disease-modifying drugs?

Please choose one of the following options:

a. Within 2 months
b. Within 3–6 months
c. Within 7–12 months
d. Greater than 12 months following diagnosis

2. In general, to what extent do you think patients should be involved in choosing their MS treatment?

Please choose one of the following options:

a. The patient is not involved, physicians should make that decision
b. The treatment options are discussed, but ultimately the physician should decide on the best option for the patient
c. Patients should select their treatment, after being informed about the treatment options

3. In general, how involved are your MS patients in the treatment decision-making process?

Please choose one of the following options:

a. Fully involved
b. Fairly involved
c. Not involved at all
4. In your opinion, what are the three most important factors to consider when prescribing an MS treatment?

a. Effectiveness in terms of relapse reduction (based on clinical trials)
b. Effectiveness based on MRI activity
c. Effectiveness in reducing disease progression (based on clinical trials)
d. Side-effect profile
e. Long-term safety profile
f. Patient programs
f. Costs
e. Other, please specify

5. In your opinion, which three factors do patients consider most important when deciding on a treatment?

a. Effectiveness in terms of relapse reduction
b. Effectiveness in reducing disease progression
c. Side-effect profile
d. Method of administration
e. Frequency of treatment
f. Influence on quality of life
g. Long-term safety profile
h. Patient programs
i. Other, please specify

6: In your opinion, what factors do MS patients consider most important?

Please arrange the following treatment goals in order of importance:
a. Longer between/less frequency of attacks/episodes/flare-ups
b. Decrease in severity of attacks/episodes/flare-ups
c. Reduction of progression of the disease
d. Maintains current status/condition
e. Prevents symptoms getting worse (e.g., cognition, fatigue)
f. Long-term disability is reduced/prolongs time to long-term disability
g. Reduction MRI lesions
h. Less reduction in total brain volume
i. Improvement in quality of life

7: Are the following (possible) treatment goals discussed during a consultation?

Please select yes or no:
 Longer between/less frequency of attacks/episodes/flare-ups
 Decrease in severity of attacks/episodes/flare-ups
 Reduction of progression of the disease
 Maintains current status/condition
 Prevents symptoms getting worse (e.g., cognition, fatigue)
 Long-term disability is reduced/prolongs time to long-term disability
 Reduction MRI lesions
 Less reduction in total brain volume
 Improvement in quality of life
 Adherence

8. Are you in need of materials (e.g., brochures, websites with accurate information) to discuss the above mentioned treatment goals with your MS patients?

Please choose one of the following options:
9. What materials do you need?

Please choose one of the following options:

a. Contact information of a patient organization
b. Brochures
c. Website with accurate information
d. Other materials, please specify

10. How well do your patients understand the relative benefits and associated risks of currently available MS treatments?

Please choose one of the following options:

a. Very well
b. Fairly well
c. Not very well
d. Not at all well

11. Please indicate what side effects of treatment mainly affect the patients’ adherence to their MS therapy?

Please select all possible options:

a. Injection-site reactions
b. Flu-like symptoms
c. Mood changes
12. Which side effect of treatment has the greatest impact on adherence to MS therapy?

Please choose one of the following options:

a. Injection-site reactions
b. Flu-like symptoms
c. Mood changes
d. Lipoatrophy
e. Chest tightness/ shortness of breath
f. Increased muscle spasms
g. Stomach and bowel problems
h. Other, please specify

13. For those selecting (a) as a response to question 11 or 12: Approximately what percentage, if any, of all your MS patients complain of injection-site reactions?

14. For those selecting (b) as a response to question 11 or 12: Approximately what percentage, if any, of all your MS patients complain of flu-like symptoms?

15. In general, do you find adherence an issue when treating MS patients?

a. Yes
b. No
16. Approximately what percentage, if any, of all your treated MS patients take a treatment break?

17. Approximately what percentage, if any, of all your treated MS patients stop their treatment?

18. For those responding with >0% to question 16 or 17: What are the main reasons for patients to take a break or stop their MS treatment?

Please select all possible options:

a. Side effects (in general)
b. Disease showing no sign of decline
c. Injection-site reactions
d. Flu-like symptoms
e. Mood changes
f. Skin reactions (for example, rash, itching, flushing)
g. Lipoatrophy
h. Increased muscle spasms
i. Shortness of breath affecting activity levels
j. Not proven to be safe in long-term
k. Cannot afford treatment
l. Other, please specify

19. For those responding with >0% to question 16 or 17: Do physical or psychological factors (eg patient’s belief in his/her MS treatment) predominantly affect the patient’s decision to take a break or stop his/her treatment?

Please choose one of the following options:
20. What (other) aspects, if any, do your MS patients generally find challenging about their current treatment regimes?

Please select all possible options:

a. Side effects (in general)

b. Injection-related issues

c. Slow response to treatment

d. Maintaining a medication schedule

e. Affording medication

f. Other, please specify

21. What do you think MS patients would cite as the most important factor that would improve their adherence to treatment?

Please choose one of the following options:

a. No more injections

b. Taking treatment less frequently

c. If their medication improves overall well-being

d. Easier to take

e. Other, please specify

22. If a patient could take the treatment less frequently, how much might the adherence to the treatment change?
a. Improve significantly
b. Improve moderately
c. No change/neither deteriorate nor improve
d. Deteriorate moderately
e. Deteriorate significantly

23. Approximately what percentage, if any, of all your treated MS patients have switched treatments (following initial prescription)?

24. For those responding >0% to question 23: What are the main reasons for patients switching to a new treatment?

Please select all possible options:

a. Side effects (in general)
b. Improved efficacy
c. Improved injection-site reactions
d. Less frequent treatment
e. Greater long-term safety profile
f. Maintaining a medication schedule
g. Other, please specify

25. Apart from efficacy, do you regularly review your MS patients’ treatment?

a. Yes
b. No

26. For those responding (a) to question 25: On average, how often do you review the treatment for your MS patients?
Please choose one of the following options:

a. More often than every 6 months
b. Between 6 months but less than 1 year
c. Between 1 year but less than 2 years
d. Between 2 years but less than 3 years
e. Between 3 years but less than 4 years
f. Between 4 years but less than 5 years
g. Every 5 or more years
h. Don’t know/varies

27. Approximately what percentage, if any, of all your MS patients ever initiate a discussion about possible other treatments for their condition?

28. Would you change your first-line MS treatment for another therapy that a patient may find easier to comply with (yes, would change/no, would not change), if it had …

Select yes/no for each option

a. … Greater efficacy
b. … Fewer side effects
c. … Greater long-term safety profile
d. … Different method of administration
e. … More side effects
f. … Reduced efficacy

29. What specific information or services, if any, do you offer your MS patients on how they may maintain or improve their overall quality of life?
Please select all possible options:

a. Moral support/advice
b. Refer to local MS support services
c. Support/information from pharmaceutical company
d. Refer to national/local patient group
e. Other, please specify

30. Specifically, what information or services, if any, do you offer your MS patients on helping them cope with the physical disabilities caused by their disease?

Please select all possible options:

a. Refer to a physiotherapist
b. Refer to the multidisciplinary team
c. Refer to appropriate healthcare professionals for further assistance
d. Other, please specify

31. And specifically, what information or services, if any, do you offer your MS patients on helping them cope with the mental impairments caused by their disease?

Please select all possible options:

a. Refer to a counselor/counseling service
b. Refer to MS support services
c. Refer to multidisciplinary team
d. Other, please specify

32. In general, do you think pharmaceutical companies give sufficient consideration with regards to the needs of MS patients when developing new treatment options?
33. Which treatment/management innovations do you believe would be likely to benefit MS patients the most if they were available?

Please choose one of the following options:

a. Oral therapy
b. New specific biological therapies
c. Mobility/disability aids
d. Stem cell transplant
e. Other, please specify

34. For those responding (a) to question 33: Why do you say that an oral therapy would be most likely to benefit MS patients if it was available?

(Free text response)