Appendix 2 Questions included in patients’ questionnaire

1. What type of treatment do you use for your MS?

Please choose one of the following options:

a. Avonex
b. Betaferon
c. Copaxone
d. Rebif 22 mcg
e. Rebif 44 mcg

2. How is your medication delivered to you?

Please choose one of the following options:

a. The medication is home-delivered by the hospital’s pharmacy
b. The medication is home-delivered by the local pharmacy
c. The medication is home-delivered by the patient program
d. I pick up the medication at the hospital’s pharmacy
e. I pick up the medication at the local pharmacy
f. The medication is administered at the hospital
g. The medication is administered at home by a nurse
h. Other, please specify

3. For how many weeks do you receive medication?

Please choose one of the following options:

a. For... weeks
b. That differs
c. I don’t know

4. How is your medication supply being monitored?

Please choose one of the following options:

a. By my pharmacist
b. I call the pharmacy myself when I need another supply
c. I go for regular check-ups at the hospital and then the pharmacy provides the right supply
d. I have in-between appointments with my doctor/nurse about my medication
e. The patient program monitors my supply
f. I don’t know
g. Other, please specify

5. Was your medication dosage adapted recently?

Please choose one of the following options:

a. Yes, the dosage has been increased
b. Yes, the dosage has been lowered
c. No
d. I don’t know

6. For those responding (a) or (b) to question 5: Why has your dosage been adapted?

Please choose one of the following options:

a. The treatment was not sufficiently effective
b. I had too many side effects
c. There is no reimbursement (anymore) for my previous dosage
d. I don’t know
7. How often do you have medication left that you can/may no longer use?

Please choose one of the following options:

a. That often happens
b. That sometimes happens
c. That seldom happens
d. That never happens
e. I don’t know

8. How long following your diagnosis did you start undergoing treatment for your MS?

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
e. Don’t know

9. How involved were you in choosing your MS treatment?

Please choose one of the following options:

a. Your doctor/nurse selected your treatment (without discussing any treatment options with you)
b. Your doctor/nurse and you discussed different treatment options and he/she recommended the one to take
c. Your doctor/nurse and you discussed different treatment options and you decided which one to take
10. For those responding (b) or (c) to question 9: When you were discussing with your doctor/nurse which MS treatment to take, what were the most important factors for you to consider?

Please select all possible options:

a. How effective the treatment would be in reducing relapses
b. How effective the treatment would be in reducing disease progression
c. Possible side effects from taking the treatment
d. How the treatment would be taken
e. How frequently the treatment would be taken
f. How it could affect your quality of life
g. Long-term safety profile of the treatment
h. The availability of a patient program and contact with other patients
i. I don’t know
j. Other, please specify

11. For those responding (b) or (c) to question 9: Please rate how important each of the following factors were to you when deciding which MS treatment to take? (Scale from 1 = ‘not important at all’ to 5 = ‘extremely important’)

a. How effective the treatment would be in reducing relapses
b. How effective the treatment would be in reducing disease progression
c. Possible side effects from taking the treatment
d. How the treatment would be taken
e. How frequently the treatment would be taken
f. How it could affect your quality of life
g. Long-term safety profile of the treatment
h. The availability of a patient program
i. The possibility to contact other patients using the treatment

j. The ‘Other’ from Q10

12. 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
j. Other, please specify

13. Have the following treatment goals been discussed with you during your consults with your neurologist/MS nurse?

Please select: sufficiently, insufficiently or not

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
j. The ‘Other’ from Q12

14. Are you in need of more (background) information about the above mentioned treatment goals?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know

15. How would you like to receive this information?

Please select all possible options:

a. Neurologist
b. MS nurse
c. Patient organization
d. Brochure
e. Website with accurate information
f. Other, please specify

16. Are you aware of both the benefits and possible side effects of your current MS treatment?

Please choose one of the following options:

a. Yes, you know both the benefits and side effects
b. No, you only know the benefits
c. No, you only know the side effects
d. No, you do not know about either

17. Apart from what you are currently taking, are you aware of any other available MS treatment(s)?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know

d. No, you do not know about either

18. For those responding (a) to question 17: How much do you know about the benefits and possible side effects of other MS treatment(s)?

Please choose one of the following options:

a. You know a lot about them
b. You know something about them
c. You know little about them
d. You know nothing about them
e. Don’t know

19. Have you ever experienced any side effects from your MS treatment?

Please choose one of the following options:

a. No
b. Yes

20. For those responding (b) to question 19: Have these side effects from your MS treatment affected your daily life?
Please choose one of the following options:

a. No
b. Yes

21. For those responding (b) to question 20: Which side effects from your MS treatment have affected your daily life the most?

Please select all possible options:

a. Flu-like symptoms
b. Tiredness/lethargy
c. Injection-site reactions (eg redness, soreness, scarring)
d. Mood changes
e. Lack of sleep/difficulty sleeping
f. Increased muscle spasms
g. Chest tightness/ Shortness of breath
h. Don’t know
i. Other, please specify

22. For those responding (a) to question 21: To what extent do flu-like symptoms affect your daily life? (Scale from 1 = ‘slightly affected’ to 5 = ‘greatly affected’)

1-5

23. For those responding (c) to question 21: To what extent do injection-site reactions affect your daily life? (Scale from 1 = ‘slightly affected’ to 5 = ‘greatly affected’)

1-5
24. Have you ever taken a break from your MS treatment, ie where you have actively decided not to take your treatment as opposed to forgetting to take it and which could last 1 day or longer?

Please choose one of the following options:

a. Yes
b. No

25. Have you ever stopped taking your MS treatment?

Please choose one of the following options:

a. Yes
b. No

26. For those responding (a) to question 24 or 25: What led to your decision to take a break or stop your MS treatment?

Please choose one of the following options:

a. Physical factors
b. Psychological factors
c. Physical and psychological factors in equal measures
d. Don’t know

27. For those responding (a) to question 24 or 25: Specifically, what were the main reasons for taking a break or stopping your MS treatment?

Please choose one of the following options:
a. Side effects from the treatment
b. The treatment was not working
c. Practical issues from taking the treatment
d. Difficulty in remembering to take the treatment
e. Convenience
f. Treatment was not proven to be safe over long-term use
g. Because an alternative/new treatment is easier to use
h. Because I was told that an alternative/new treatment would be at least as effective
i. Because an alternative/new treatment is cheaper for the hospital
j. Because the hospital prefers another treatment
k. Because I am doing better and my disease is calm
l. Don’t know
m. Other, please specify

28. For those responding (a) to question 27: Specifically, what side effects did you experience which made you take a break or stop your MS treatment?

Please choose one of the following options:

a. Flu-like symptoms
b. Tiredness/lethargy
c. Injection-site reactions (eg, redness, soreness, scarring)
d. Mood changes
e. Lack of sleep/difficulty sleeping
f. Increased muscle spasms
g. Chest tightness/shortness of breath
h. Don’t know
i. Other, please specify
29. What do you consider is the most difficult aspect of taking your current MS treatment?

Please choose one of the following options:

a. Fitting the injection around your lifestyle (work, holiday, leisure, etc)

b. Doing your daily activities while trying to manage the side effects from taking the treatment

c. Being physically able to inject it

d. Being emotionally able to inject it

e. Managing the emotional side effects from taking the treatment

f. Practically managing the injections (storage, disposing of needles, etc)

g. None in particular

h. Don’t know

30. Apart from any side effects of the MS treatment that you may have experienced, do you ever discuss any other aspect of your MS treatment with your doctor/nurse?

Please choose one of the following options:

a. Yes

b. No

c. Don’t know

31. What do you consider are the most important factors concerning your MS treatment that can help improve your quality of life?

Please select all possible options:

a. No more injections/take alternative form of treatment

b. Good safety profile when used over a long period of time

c. None or fewer side effects
32. Please rank these factors in order of their importance with regards to their effect on improving your likelihood to take your MS treatment
(rank 1 to 4: 1 being ‘most important’, 4 being ‘least important’)

- a. No more injections/take alternative form of treatment
- b. Good safety profile when used over a long period of time
- c. None or fewer side effects
- d. Less frequent dosing

33. How much would your life in general change if you could take your treatment less frequently?

Please choose one of the following options:
- a. Improve significantly
- b. Improve moderately
- c. No change at all
- d. Worsen moderately
- e. Worsen significantly
- f. Don’t know

34. How much would your emotional well-being change if you could take your treatment less frequently?

Please choose one of the following options:
- a. Improve significantly
- b. Improve moderately
35. What sources or services, if any, do you use to get more information on how to manage your MS treatment more effectively?

Please select all possible options:

a. Neurologist
b. MS Society/associations
c. Online source/websites
d. Literature (books, magazines, etc)
e. General practitioner (GP)
f. MS nurse
g. Nurse from the patient program
h. Family/friends
i. Literature from pharmaceutical/drug company/manufacturer
j. Pharmaceutical/drug company/manufacturer’s website
k. None
l. Don’t know
m. Other, please specify

36. Does your doctor/nurse regularly review your MS treatment?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know

37. For those responding (a) to question 36: On average, how often does your doctor/nurse review your MS treatment with you?

Please choose one of the following options:

a. More often than every 3 months
b. Every 3–6 months
c. Every 7–9 months
d. Every 10–12 months (once a year)
e. Every 13–23 months
f. Once every 24 months (2 years)
g. Less often than once every 2 years
h. Don’t know

38. Have you ever initiated a discussion with your doctor/nurse about other MS treatments?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know

39. Have you ever asked your doctor/nurse to change your MS treatment?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know
40. For those responding (a) to question 39: What was your doctor’s/nurse’s response to your request to change your MS treatment? What did he/she say and do?

(Free text response)

41. In general, to what extent, if at all, has your physical well-being been affected by your MS?

Please choose one of the following options:

a. Improved
b. Not changed
c. Worsened moderately
d. Worsened significantly
e. Don’t know

42. In general, to what extent, if at all, has your emotional well-being been affected by your MS?

Please choose one of the following options:

a. Improved
b. Not changed
c. Worsened moderately
d. Worsened significantly
e. Don’t know

43. In general, how much has your MS affected your overall quality of life?

Please choose one of the following options:

a. Improved
b. Not changed
c. Worsened moderately
d. Worsened significantly
e. Don’t know

44. Which new treatment/innovation do you believe would be likely to benefit you the most, as an MS patient, if it was available?

Please choose one of the following options:

a. Oral therapy (tablet/capsule/pill, etc)
b. Stem cell therapy/transplant
c. Monthly or annual intravenous injections/infusion
d. New monoclonal antibodies
e. Don’t know
f. Other

45. For those responding (b) to question 44: Why do you say that?

(Free text response)

46. Do you think pharmaceutical/drug companies give sufficient consideration to the needs of MS patients when developing new treatments?

Please choose one of the following options:

a. Yes
b. No
c. Don’t know

47. For those responding (b) to question 46: Why do you say that?
(Free text response)

**48. For those responding (a) to question 44: Why would an oral therapy benefit you the most?**

Please choose one of the following options:

- a. No more injections
- b. Take treatment less frequently
- c. Easier to take/remember to take
- d. Don’t know
- e. Other

**49. If an oral treatment was available but less effective than the current injectable forms, if you had the choice, would you prefer to take either the oral or injectable form?**

Please choose one of the following options:

- a. Injectable form
- b. Oral form
- c. No preference/don’t mind either
- d. Don’t know