

Appendix 1. Questionnaires

1.1 Demographic questionnaire

<u>What is your gender?</u>	1. Male <input type="checkbox"/>	2. Female <input type="checkbox"/>																
<u>What is your age?</u>	1. 18 to 24 <input type="checkbox"/> 2. 25 to 34 <input type="checkbox"/> 3. 35 to 44 <input type="checkbox"/> 4. 45 to 54 <input type="checkbox"/> 5. 55 to 64 <input type="checkbox"/> 6. 65 to 75 <input type="checkbox"/> 7. 75 or older <input type="checkbox"/>																	
<u>What is your ethnicity?</u>	<table border="0"> <tr> <td>1. White - British <input type="checkbox"/></td> <td>9. Asian or Asian British - Pakistani <input type="checkbox"/></td> </tr> <tr> <td>2. White - Irish <input type="checkbox"/></td> <td>10. Asian or Asian British - Bangladeshi <input type="checkbox"/></td> </tr> <tr> <td>3. Any other white background <input type="checkbox"/></td> <td>11. Any Other Asian Background <input type="checkbox"/></td> </tr> <tr> <td>4. Mixed – White & Black Caribbean <input type="checkbox"/></td> <td>12. Black or Black British - Caribbean <input type="checkbox"/></td> </tr> <tr> <td>5. Mixed – White & Black African <input type="checkbox"/></td> <td>13. Black or Black British - African <input type="checkbox"/></td> </tr> <tr> <td>6. Mixed – White & Asian <input type="checkbox"/></td> <td>14. Any Other Black background <input type="checkbox"/></td> </tr> <tr> <td>7. Any other mixed background <input type="checkbox"/></td> <td>15. Chinese <input type="checkbox"/></td> </tr> <tr> <td>8. Asian or Asian British - Indian <input type="checkbox"/></td> <td>16. Any other ethnic group (please specify) <input type="checkbox"/> _____</td> </tr> </table>		1. White - British <input type="checkbox"/>	9. Asian or Asian British - Pakistani <input type="checkbox"/>	2. White - Irish <input type="checkbox"/>	10. Asian or Asian British - Bangladeshi <input type="checkbox"/>	3. Any other white background <input type="checkbox"/>	11. Any Other Asian Background <input type="checkbox"/>	4. Mixed – White & Black Caribbean <input type="checkbox"/>	12. Black or Black British - Caribbean <input type="checkbox"/>	5. Mixed – White & Black African <input type="checkbox"/>	13. Black or Black British - African <input type="checkbox"/>	6. Mixed – White & Asian <input type="checkbox"/>	14. Any Other Black background <input type="checkbox"/>	7. Any other mixed background <input type="checkbox"/>	15. Chinese <input type="checkbox"/>	8. Asian or Asian British - Indian <input type="checkbox"/>	16. Any other ethnic group (please specify) <input type="checkbox"/> _____
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<u>Marital Status</u>	<table border="0"> <tr> <td>1. Single <input type="checkbox"/></td> <td>5. Co-habiting <input type="checkbox"/></td> </tr> <tr> <td>2. Married <input type="checkbox"/></td> <td>6. Civil partnership <input type="checkbox"/></td> </tr> </table>		1. Single <input type="checkbox"/>	5. Co-habiting <input type="checkbox"/>	2. Married <input type="checkbox"/>	6. Civil partnership <input type="checkbox"/>												
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<p>2. Fingolimod (Gilenya)</p>	<p>1. Currently receiving this treatment <input type="checkbox"/></p>	<p>2. Have tried this treatment in the past but now stopped <input type="checkbox"/></p>	<p>3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/></p>	<p>4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/></p>	<p>5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/></p>
<p>3 Alemtuzumab (Lemtrada)</p>	<p>1. Currently receiving this treatment <input type="checkbox"/></p>	<p>2. Have tried this treatment in the past but now stopped <input type="checkbox"/></p>	<p>3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/></p>	<p>4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/></p>	<p>5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/></p>
<p>4. Beta interferon (eg. Avonex, Rebif, Betaferon, Extavia)</p>	<p>1. Currently receiving this treatment <input type="checkbox"/></p>	<p>2. Have tried this treatment in the past but now stopped <input type="checkbox"/></p>	<p>3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/></p>	<p>4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/></p>	<p>5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/></p>
<p>5. Dimethyl Fumarate (Tecfidera/BG-12)</p>	<p>1. Currently receiving this treatment <input type="checkbox"/></p>	<p>2. Have tried this treatment in the past but now stopped <input type="checkbox"/></p>	<p>3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/></p>	<p>4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/></p>	<p>5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/></p>

			prescribed it <input type="checkbox"/>	prescribed it <input type="checkbox"/>	
6. Glatiramer Acetate (Copaxone)	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
7. Teriflunomide (Aubagio)	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
8. Laquinimod	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
9. Stem Cells	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but	3. I have knowledge of this treatment but have	4. I have no knowledge of this treatment and have	5. I am either on this treatment or placebo as

		now stopped <input type="checkbox"/>	never been prescribed it <input type="checkbox"/>	never been prescribed it <input type="checkbox"/>	part of a clinical trial <input type="checkbox"/>
10. Azathioprine	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
11. IVIg (intravenous innumoglobulin)	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
12. Mitoxantrone	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>

13. Cyclophosphamide	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
14. Zenapax (Daclizumab)	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>
15. Ocrelizumab	1. Currently receiving this treatment <input type="checkbox"/>	2. Have tried this treatment in the past but now stopped <input type="checkbox"/>	3. I have knowledge of this treatment but have never been prescribed it <input type="checkbox"/>	4. I have no knowledge of this treatment and have never been prescribed it <input type="checkbox"/>	5. I am either on this treatment or placebo as part of a clinical trial <input type="checkbox"/>

1.3 Treatment Status

Question asked: 'With reference to treatment, which of the following options best reflects your *current* situation?'

Please tick one box.

1. Satisfied to continue with existing treatment <input type="checkbox"/>	2. On treatment but considering a treatment switch <input type="checkbox"/>	3. Not on treatment but considering treatment options <input type="checkbox"/>	4. Not on treatment and not considering treatment <input type="checkbox"/>
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1.4 DC (SURE scale)

Further to the answer you gave (above) referencing treatment choice:

1. Do you feel sure about the best choice for you?	1. Yes <input type="checkbox"/>	2. No <input type="checkbox"/>
2. Do you know the benefits and risks of each option?	1. Yes <input type="checkbox"/>	2. No <input type="checkbox"/>
3. Are you clear about which benefits and risks matter most to you?	1. Yes <input type="checkbox"/>	2. No <input type="checkbox"/>
4. Do you have enough support and advice to make a choice?	1. Yes <input type="checkbox"/>	2. No <input type="checkbox"/>

1.5 Decisional Regret Scale

Based upon your current treatment status (even if you are not on treatment), please show how you feel about these statements by selecting a single options from each row of statements below:

1. It was the right decision	1 Strongly Agree <input type="checkbox"/>	2 Agree <input type="checkbox"/>	3 Neither Agree Nor Disagree <input type="checkbox"/>	4 Disagree <input type="checkbox"/>	5 Strongly Disagree <input type="checkbox"/>
2. I regret the choice that was made	1 Strongly Agree <input type="checkbox"/>	2 Agree <input type="checkbox"/>	3 Neither Agree Nor Disagree <input type="checkbox"/>	4 Disagree <input type="checkbox"/>	5 Strongly Disagree <input type="checkbox"/>

3. I would go for the same choice if I had to do it over again	1 Strongly Agree <input type="checkbox"/>	2 Agree <input type="checkbox"/>	3 Neither Agree Nor Disagree <input type="checkbox"/>	4 Disagree <input type="checkbox"/>	5 Strongly Disagree <input type="checkbox"/>
4. The choice did me a lot of harm	1 Strongly Agree <input type="checkbox"/>	2 Agree <input type="checkbox"/>	3 Neither Agree Nor Disagree <input type="checkbox"/>	4 Disagree <input type="checkbox"/>	5 Strongly Disagree <input type="checkbox"/>
5. The decision was a wise one	1 Strongly Agree <input type="checkbox"/>	2 Agree <input type="checkbox"/>	3 Neither Agree Nor Disagree <input type="checkbox"/>	4 Disagree <input type="checkbox"/>	5 Strongly Disagree <input type="checkbox"/>

1.6 Control Preference Scale

Which of the following scenarios best fits how you would usually reach a decision about treatment either now or in the past?

A - B - C - D - E -



This marks the end of the questionnaire. Please kindly double-check that you have answered every question as described.

Once again, thank you for taking the time to complete the research.

References

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HEESEN, C., KASPER, J., SEGAL, J., KOPKE, S. & MUHLHAUSER, I. 2004. Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Mult Scler*, 10, 643-50.