

MSOC Website Survey

Please read the participant information below before giving your consent to participate by selecting "I agree" at the bottom of the page.

I have read and understand the participant information form.

I freely agree to participate in this project according to the conditions described.

MSOC Website Survey

Welcome to the MSOC - RCT study questionnaire.

Please take a moment to complete all questions as your opinion matters to us. We will utilise your responses to analyse the effects of lifestyle on survey respondents' quality of life and health.

If you are unsure about how to answer a question, please give the best answer you can and write a comment in the additional comments field. Alternatively, you can contact our research team at The University of Melbourne if you have any difficulties.

You may exit and re-enter the survey at your leisure until completed, but please take care not to miss any questions by mistake.

Thank you,

**Dr Sandra Neate
(Principle investigator)**

1. Please provide your email address and location details.

(please note that this information is confidential and all surveys will be de-identified)

Name:

City/Town:

State:

Country:

Email Address:

Mobile phone:

2. What is your year of birth?

3. Has a Medical Doctor formally diagnosed you with Multiple Sclerosis (MS)?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

Tick as appropriate

4. In which year did a specialist diagnose you with MS?

If unsure, please provide approximate year

5. Which type of MS were you first diagnosed with?

Relapsing-remitting	<input type="checkbox"/>
Secondary progressive	<input type="checkbox"/>
Primary progressive	<input type="checkbox"/>
Progressive relapsing	<input type="checkbox"/>
Unsure	<input type="checkbox"/>

6. Which type of MS do you have now?

Relapsing-remitting	<input type="checkbox"/>
Secondary progressive	<input type="checkbox"/>
Primary progressive	<input type="checkbox"/>
Progressive relapsing	<input type="checkbox"/>
Unsure	<input type="checkbox"/>

7. Do you follow a specific diet for your MS?

If so, what diet do you follow for your MS?

8. What is your country of birth?

10. How tall are you? Please report EITHER centimetres or inches.

	Centimeters	Inches
Height	<input type="text"/>	<input type="text"/>

Other (please specify unit of measurement)

11. What is your weight? Please report EITHER kilograms or pounds.

	Kilograms	Pounds
Weight	<input type="text"/>	<input type="text"/>

Other (please specify unit of measurement)

12. The following is a list of common problems. Please indicate if you currently have the problem in the first column. If you do not have the problem, skip to the next problem. If you do have the problem, please indicate in the second column if you receive medications or some other type of treatment for the problem. In the third column indicate if the problem limits any of your activities.

	Do you have the condition?	Do you receive treatment for it?	Does it limit your activities?
Heart Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lung disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ulcer or stomach disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Liver disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anaemia or other blood disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arthritis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Back pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other medical problems (please specify if you receive treatment Y/N and if it limits your activities Y/N)

13. What is your marital status?

Married	<input type="checkbox"/>
Cohabiting/partnered	<input type="checkbox"/>
Separated/divorced/widower	<input type="checkbox"/>
Single	<input type="checkbox"/>

14. What is the highest level of education you have completed?

No formal schooling	<input type="checkbox"/>
Primary school	<input type="checkbox"/>
Secondary school	<input type="checkbox"/>
Vocational training	<input type="checkbox"/>
Bachelor's degree	<input type="checkbox"/>
Post-grad degree	<input type="checkbox"/>

15. What is your current employment status?

Work full-time	<input type="checkbox"/>
Work part-time	<input type="checkbox"/>
Self-employed	<input type="checkbox"/>
Paid work, unspecified	<input type="checkbox"/>
Stay at home parent/carer	<input type="checkbox"/>
Full-time student	<input type="checkbox"/>
Unemployed, seeking employment	<input type="checkbox"/>
Unemployed, not seeking employment	<input type="checkbox"/>
Retired due to age	<input type="checkbox"/>
Retired due to medical reasons/disability	<input type="checkbox"/>
Work status not clearly specified	<input type="checkbox"/>

16. Do you currently smoke cigarettes of any tobacco products?

Never smoked	<input type="checkbox"/>
Ex-smoker	<input type="checkbox"/>
Current smoker	<input type="checkbox"/>

17. What is the average number of cigarettes per day you smoke or used smoke?

< 1 per day	<input type="checkbox"/>
1 – 5 per day	<input type="checkbox"/>
6 – 10 per day	<input type="checkbox"/>
11 – 15 per day	<input type="checkbox"/>
16 – 20 per day	<input type="checkbox"/>
> 20 per day	<input type="checkbox"/>

Dietary Habits Questionnaire

Please complete the following questions by selecting the option that best applies to you.

For the questions related to oils and fats:

* Vegetable oil - eg. coconut, palm

** Mono-unsaturated oil - eg. olive, canola, pecan, almond, peanut

** Polyunsaturated oil - eg. corn, soy, cottonseed, safflower, sunflower, walnut, flaxseed, fish

18. How many days a week do you eat a high fibre breakfast cereal? (e.g. rolled oats, Weet-bix TM, Allbran TM, untoasted muesli)

Never/hardly	<input type="checkbox"/>
<1 day a week	<input type="checkbox"/>
1-2 days a week	<input type="checkbox"/>
3-5 days a week	<input type="checkbox"/>
6+ days a week	<input type="checkbox"/>

19. How often do you eat or use wholemeal or wholegrain bread in preference to white bread?

Never	<input type="checkbox"/>
Rarely	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>
Usually	<input type="checkbox"/>
Always	<input type="checkbox"/>

20. How often do you eat cereal e.g. pasta, rice, noodles, couscous, as part of your main meal?

Never	<input type="checkbox"/>
Rarely	<input type="checkbox"/>
1-2 days a week	<input type="checkbox"/>
3-4 days a week	<input type="checkbox"/>
5+ days a week	<input type="checkbox"/>

21. How many serves of vegetables would you eat in a typical day?

None	<input type="checkbox"/>
<1 serve	<input type="checkbox"/>
1-2 serves	<input type="checkbox"/>
3-4 serves	<input type="checkbox"/>
5+ serves	<input type="checkbox"/>

22. How many different types of vegetable would you eat on a typical day?

None	<input type="checkbox"/>
1-2 types	<input type="checkbox"/>
3 types	<input type="checkbox"/>
4 types	<input type="checkbox"/>
5+ types	<input type="checkbox"/>

23. How many times a week do you eat two or more pieces of fruit a day?

Never/hardly	<input type="checkbox"/>
<1 day a week	<input type="checkbox"/>
1-2 days a week	<input type="checkbox"/>
3-5 days a week	<input type="checkbox"/>
6+ days a week	<input type="checkbox"/>

24. How many days a week do you eat legumes? (e.g. chick peas, baked beans, three bean mix, lentils, split peas, dried beans etc)

Never/hardly ever	<input type="checkbox"/>
1 day / month	<input type="checkbox"/>
1 day / fortnight	<input type="checkbox"/>
1 day / week	<input type="checkbox"/>
2-3 days / week	<input type="checkbox"/>
4+ days / week	<input type="checkbox"/>

25. How often do you include raw nuts or seeds such as pepitas, sunflower seeds, and linseeds?

Never	<input type="checkbox"/>
Rarely	<input type="checkbox"/>
1-2 days a week	<input type="checkbox"/>
3-4 days a week	<input type="checkbox"/>
5+ days a week	<input type="checkbox"/>

26. When having milk, yoghurt or cheese (from animal sources), how often do you eat or use reduced- fat or low fat products in preference to regular products?

Never	<input type="checkbox"/>
Rarely	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>
Usually	<input type="checkbox"/>
Always	<input type="checkbox"/>

27. How many days a week do you eat fish?

Never/hardly ever	<input type="checkbox"/>
<1 day / week	<input type="checkbox"/>
1 day / week	<input type="checkbox"/>
2 days / week	<input type="checkbox"/>
3+ days / week	<input type="checkbox"/>

28. If you use a spread on bread or cracker biscuits, which type of spread would you usually use?

Don't use spreads	<input type="checkbox"/>
Butter	<input type="checkbox"/>
Cream cheese	<input type="checkbox"/>
Margarine (mono/polyunsaturated, sterol)	<input type="checkbox"/>
Avocado	<input type="checkbox"/>

29. How many days a week do you eat processed meats (e.g. bacon, sausages, salami, ham, frankfurts, or pate)?

Don't eat meat	<input type="checkbox"/>
4+ / week	<input type="checkbox"/>
2-3 days / week	<input type="checkbox"/>
1 day / week	<input type="checkbox"/>
<1 day / week	<input type="checkbox"/>

30. What type of salad dressing do normally use?

Full fat commercial dressing	<input type="checkbox"/>
Reduced fat commercial	<input type="checkbox"/>
Mono/polyunsaturated oil base	<input type="checkbox"/>
Don't use dressing on salad	<input type="checkbox"/>

31. What type of cooked sauces do you normally use? (You may select more than one)

Vegetable/tomato-based sauces	<input type="checkbox"/>
Reduced fat milk-based	<input type="checkbox"/>
Gravy from commercial powder	<input type="checkbox"/>
Gravy from pan dripping	<input type="checkbox"/>
Cream or full cream milk- based	<input type="checkbox"/>
Sauces with coconut milk	<input type="checkbox"/>
I don't use cooked sauces	<input type="checkbox"/>

32. How often do you trim all the visible fat off the meat you eat (OR purchase pre-trimmed meat) and remove the skin from chicken before cooking?

Don't eat meat	<input type="checkbox"/>
Never	<input type="checkbox"/>
Rarely	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>
Usually	<input type="checkbox"/>
Always	<input type="checkbox"/>
Don't eat meat	<input type="checkbox"/>

33. Which of the following cooking fats do you normally use?

Don't use fat in cooking	<input type="checkbox"/>
Butter	<input type="checkbox"/>
Solid frying fat	<input type="checkbox"/>
Vegetable oil	<input type="checkbox"/>
Mono/polyunsaturated oil	<input type="checkbox"/>
Sterol margarine	<input type="checkbox"/>
Spray oil	<input type="checkbox"/>

34. Which of the following cooking methods do you commonly use when cooking?
(You may select more than one)

Steaming	<input type="checkbox"/>
Poaching	<input type="checkbox"/>
Microwaving	<input type="checkbox"/>
Casseroles	<input type="checkbox"/>
Grilling	<input type="checkbox"/>
Stir frying	<input type="checkbox"/>
Dry roasting	<input type="checkbox"/>
Deep frying	<input type="checkbox"/>
Shallow frying	<input type="checkbox"/>
Roasting in fat	<input type="checkbox"/>

35. How often do you eat foods like pastries, cake, sweet biscuits or croissants?

6+ days / week	<input type="checkbox"/>
3-5 days /week	<input type="checkbox"/>
1-2 days /week	<input type="checkbox"/>
<1 day /week	<input type="checkbox"/>
Never/hardly ever	<input type="checkbox"/>

36. How many days a week do you eat take-away style foods such as fried or BBQ chicken, fish and chips, Chinese, pizza, hamburgers etc?

5+ days / week	<input type="checkbox"/>
3-4 days /week	<input type="checkbox"/>
1-2 days /week	<input type="checkbox"/>
<1 day /week	<input type="checkbox"/>
Never/hardly ever	<input type="checkbox"/>

37. Which of the following foods do you eat most often as snacks between meals?

Chocolate bars	<input type="checkbox"/>
Crisps (chips)/fries	<input type="checkbox"/>
Roasted nuts	<input type="checkbox"/>
Sweet biscuits, cake	<input type="checkbox"/>
Low fat (dairy) yoghurts	<input type="checkbox"/>
Olives, raw nuts, seeds	<input type="checkbox"/>
Fruit, dried fruit	<input type="checkbox"/>
Fruit bread, English muffins	<input type="checkbox"/>
I don't snack between meals	<input type="checkbox"/>
Other	<input type="checkbox"/>

Other, specify

38. How often do you eat oily fish such as sardines, mackerel, herring, salmon, tuna or trout?

Never	<input type="checkbox"/>
<1 day /week	<input type="checkbox"/>
1-2 days /week	<input type="checkbox"/>
3-4 days /week	<input type="checkbox"/>
5+ days /week	<input type="checkbox"/>

39. Please refer to this guide for the definition of a standard drink

Full strength beer or premixed drinks with approx 5% alcohol: 285ml glass = 1

Low alcohol beer with approx 2.5% alcohol: 285ml glass = 0.5

Wine with approx 13% alcohol: 100ml glass = 1

Spirits/liqueur with 35-40% alcohol: 30ml nip or equivalent mixed spirits = 1

How often do you usually drink alcohol on a day when you drink alcohol?

Have never drunk	<input type="checkbox"/>
Never drink currently	<input type="checkbox"/>
Drink rarely	<input type="checkbox"/>
<1 day/month	<input type="checkbox"/>
1 day/month	<input type="checkbox"/>
2 days/month	<input type="checkbox"/>
3 days/month	<input type="checkbox"/>
<1 day/week	<input type="checkbox"/>
1 day/week	<input type="checkbox"/>
2 days/week	<input type="checkbox"/>
3 days/week	<input type="checkbox"/>
4 days/week	<input type="checkbox"/>
5 days/week	<input type="checkbox"/>
6 days/week	<input type="checkbox"/>
Every day	<input type="checkbox"/>

How many standard drinks do you normally have on a day when you drink alcohol?

Not applicable	<input type="checkbox"/>
0.5	<input type="checkbox"/>
1	<input type="checkbox"/>
2	<input type="checkbox"/>
3	<input type="checkbox"/>
4	<input type="checkbox"/>
5	<input type="checkbox"/>
6	<input type="checkbox"/>
7	<input type="checkbox"/>
8	<input type="checkbox"/>
9	<input type="checkbox"/>

How often do you usually drink alcohol **heavily** on a day when you drink alcohol?

Have never drank	<input type="checkbox"/>
Never drink currently	<input type="checkbox"/>
Drink rarely	<input type="checkbox"/>
<1 day/month	<input type="checkbox"/>
1 day/month	<input type="checkbox"/>
2 days/month	<input type="checkbox"/>
3 days/month	<input type="checkbox"/>
<1 day/week	<input type="checkbox"/>
1 day/week	<input type="checkbox"/>
2 days/week	<input type="checkbox"/>
3 days/week	<input type="checkbox"/>
4 days/week	<input type="checkbox"/>
5 days/week	<input type="checkbox"/>
6 days/week	<input type="checkbox"/>
Every day	<input type="checkbox"/>

How many standard drinks do you normally have on a day when you drink alcohol **heavily**?

Not applicable	<input type="checkbox"/>
0.5	<input type="checkbox"/>
1	<input type="checkbox"/>
2	<input type="checkbox"/>
3	<input type="checkbox"/>
4	<input type="checkbox"/>
5	<input type="checkbox"/>
6	<input type="checkbox"/>
7	<input type="checkbox"/>
8	<input type="checkbox"/>
9	<input type="checkbox"/>

Omega 3 Intake

40. Do you take Omega-3 supplements?

YES	NO

Tick as appropriate

41. Which type of Omega-3 supplements do you take? (You may select more than one option)

Fish oil

Flaxseed oil

High potency fish oil

Other (please specify)

42. In the last 12 months, what total dose of Omega-3 supplements (as standard strength fish oil or flaxseed oil measured in grams or mls) do you take on average per day?

_____ (grams)

_____ (mls)

Vitamin D Intake

43. Do you take vitamin D supplements?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

Tick as appropriate

44. What is the typical dose of vitamin D supplement you take?

None	<input type="checkbox"/>
<2000 IU/d	<input type="checkbox"/>
2000 – 5000 IU/d	<input type="checkbox"/>
5000 IU/d or greater	<input type="checkbox"/>

45. If you do take vitamin D supplements, how frequently do you take supplements?

Don't take	<input type="checkbox"/>
Once a month	<input type="checkbox"/>
Once every 2 weeks	<input type="checkbox"/>
1 day a week	<input type="checkbox"/>
2 days a week	<input type="checkbox"/>
3 days a week	<input type="checkbox"/>
4 days a week	<input type="checkbox"/>
5 days a week	<input type="checkbox"/>
6 days a week	<input type="checkbox"/>
Everyday	<input type="checkbox"/>

Physical activity (IPAQ)

Please answer the following questions about physical activity even if you do not consider yourself to be an active person or MS significantly limits your ability to exercise.

46. During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling? Think about only those physical activities that you did for at least 10 minutes at a time.

Never	<input type="checkbox"/>
1 day a week	<input type="checkbox"/>
2 days a week	<input type="checkbox"/>
3 days a week	<input type="checkbox"/>
4 days a week	<input type="checkbox"/>
5 days a week	<input type="checkbox"/>
6 days a week	<input type="checkbox"/>
Everyday	<input type="checkbox"/>

47. How much time in total did you usually spend on one of those days doing vigorous physical activities?

Number of hours and minutes

Hours

Minutes

48. Again, think only about those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

Never	<input type="checkbox"/>
1 day a week	<input type="checkbox"/>
2 days a week	<input type="checkbox"/>
3 days a week	<input type="checkbox"/>
4 days a week	<input type="checkbox"/>
5 days a week	<input type="checkbox"/>
6 days a week	<input type="checkbox"/>
Everyday	<input type="checkbox"/>

49. How much time in total did you usually spend on one of those days doing moderate physical activities?

Number of hours and minutes Hours Minutes

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50. During the last 7 days, on how many days did you walk for at least 10 minutes at a time? This includes walking at work and at home, walking to travel from place to place, and any other walking that you did for sport, exercise or leisure.

Never	<input type="checkbox"/>
1 day a week	<input type="checkbox"/>
2 days a week	<input type="checkbox"/>
3 days a week	<input type="checkbox"/>
4 days a week	<input type="checkbox"/>
5 days a week	<input type="checkbox"/>
6 days a week	<input type="checkbox"/>
Everyday	<input type="checkbox"/>

51. How much time in total did you usually spend walking on one of those days?

Number of hours and minutes Hours Minutes

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52. During the last 7 days, on an average weekday, how much time in total did you usually spend sitting during the day? This includes time spent sitting at a desk, visiting friends, reading, travelling on a bus or sitting or lying down to watch television (do not include sleeping).

Number of hours and minutes Hours Minutes

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Mindfulness Adherence Questionnaire

The following 6 questions are designed to measure the quantity and quality of your formal meditation practice (eg. sitting meditation)

53. How many times did you do formal meditation practice in the past week?

Never	<input type="checkbox"/>
Less than once a week	<input type="checkbox"/>
1 - 2 times per week	<input type="checkbox"/>
3 - 4 times per week	<input type="checkbox"/>
5 - 6 times per week	<input type="checkbox"/>
Everyday	<input type="checkbox"/>
Unsure	<input type="checkbox"/>

54. What was the average duration of each meditation session?

Number of hours and minutes

Hours

Minutes

Sun Exposure

The following questions are designed to determine the amount of sun exposure you receive.

55. How many days per week were you out in the sun?

During last summer days

During last winter days

56. How long on average were you out in the sun on these days?

During last summer

None	<input type="checkbox"/>
1 – 15 minutes	<input type="checkbox"/>
16 – 30 minutes	<input type="checkbox"/>
31 – 60 minutes	<input type="checkbox"/>
> 60 minutes	<input type="checkbox"/>

57. How long on average were you out in the sun on these days?

During last winter

None	<input type="checkbox"/>
1 – 15 minutes	<input type="checkbox"/>
16 – 30 minutes	<input type="checkbox"/>
31 – 60 minutes	<input type="checkbox"/>
> 60 minutes	<input type="checkbox"/>

58. Do you intentionally get more sun exposure to raise your vitamin D level?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

Tick as appropriate

MS-related medications

The following is an alphabetic list of common medications/therapies (with trade names in brackets) used to manage MS. Please select the medication you currently take, or have previously taken and how long you have used this medication in total. Please skip over any medications you have never used.

59. Medication	Current use	Previous use
Adrenocorticotrophic hormone (ACTH, Acthar®)	<input type="checkbox"/>	<input type="checkbox"/>
Alemtuzumab (Campath®, Lemtrada®)	<input type="checkbox"/>	<input type="checkbox"/>
Autologous stem cell transplantation	<input type="checkbox"/>	<input type="checkbox"/>
Azathioprine (Imuran®, Azasan®)	<input type="checkbox"/>	<input type="checkbox"/>
Dimethyl Fumarate (BG-12, Tecfidera®)	<input type="checkbox"/>	<input type="checkbox"/>
Cladribine (Leustat®, Movectro®, Mavenclad®)	<input type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan®, Revimmune)	<input type="checkbox"/>	<input type="checkbox"/>
Daclizumab (Zenapax®)	<input type="checkbox"/>	<input type="checkbox"/>
Diroximel fumarate (Vumerity®)	<input type="checkbox"/>	<input type="checkbox"/>
Fampridine (Fampyra®, Ampyra®)	<input type="checkbox"/>	<input type="checkbox"/>
Fingolimod (FTY-720, Gilenya®)	<input type="checkbox"/>	<input type="checkbox"/>
Glatiramer Acetate (Copaxone®, Glatopa©)	<input type="checkbox"/>	<input type="checkbox"/>
Interferons (Avonex®, Betaferon®, Betaseron®, Extavia®, Rebif®, Plegridy®)	<input type="checkbox"/>	<input type="checkbox"/>
Laquinimod (Nerventra®)	<input type="checkbox"/>	<input type="checkbox"/>
Low-dose Naltrexone (LDN)	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate (Folex, Matrex®, Rheumatrex®, Trexall®)	<input type="checkbox"/>	<input type="checkbox"/>
Minocycline (Minomycin)	<input type="checkbox"/>	<input type="checkbox"/>
Mitoxantrone (Novantrone®)	<input type="checkbox"/>	<input type="checkbox"/>
Monomethyl fumarate (Bafiertaim®)	<input type="checkbox"/>	<input type="checkbox"/>

Medication	Current use	Previous use
Mycophenolate Mofetil (Cellcept®)	<input type="checkbox"/>	<input type="checkbox"/>
Natalizumab (Tysabri®)	<input type="checkbox"/>	<input type="checkbox"/>
Ocrelizumab (Ocrevus®)	<input type="checkbox"/>	<input type="checkbox"/>
Ofatumumab (Kesimpta®)	<input type="checkbox"/>	<input type="checkbox"/>
Ozimod (Zeposia®)	<input type="checkbox"/>	<input type="checkbox"/>
Peginterferon Beta-1a	<input type="checkbox"/>	<input type="checkbox"/>
Plasmapheresis / Plasma exchange	<input type="checkbox"/>	<input type="checkbox"/>
Rituximab (Rituxan®)	<input type="checkbox"/>	<input type="checkbox"/>
Siponimod (Mayzent®)	<input type="checkbox"/>	<input type="checkbox"/>
Steroids (Prednisone, Prednisolone)	<input type="checkbox"/>	<input type="checkbox"/>
Teriflunomide (Aubagio®)	<input type="checkbox"/>	<input type="checkbox"/>

60. Other MS-specific therapies (please specify whether currently or previously taken)

61. Please indicate if you regularly take prescription medication, over-the-counter (non- prescription) medication or herbal remedies for the following conditions associated with MS:

(tick appropriate medication)

Medication	Prescription	Over-the-counter	Herbal remedy
Depression			
Anxiety			
Headaches			
Pain (other than headaches)			
Fatigue			
Difficulty sleeping at night			
Bladder problems			
Bowel problems			
Spasticity			
Other			

Pearlin Mastery Scale

The following 7 statements are designed to represent your experience of your ability to control and master things in your life. Please choose one of the 4 options that best represents your experience. Do not spend too much time thinking about your answer as your immediate response is likely to be the most accurate.

	Strongly agree	Agree	Disagree	Strongly disagree
62. There is really no way I can solve some of the problems I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Sometimes I feel that I'm being pushed around in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. I have little control over the things that happen to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. I can do just about anything I really set my mind to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. I often feel helpless in dealing with the problems of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. What happens to me in the future mostly depends on me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. There is little I can do to change many of the important things in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Patient-determined disease steps (PDDS)

69. Please read the choices listed below and choose the one that best describes your own situation. This scale focuses mainly on how well you walk. You might not find a description that reflects your condition exactly, but please mark the one category that describes your situation the closest. 25 feet is equal to 7.6metres.

- Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed
- Mild Disability:** I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle
- Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways
- Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack
- Early Cane:** I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks
- Late Cane:** To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto our furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.
- Bilateral Support:** To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.
- Wheelchair/Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker
- Bedridden:** I am unable to sit in a wheelchair for more than one hour.

Multiple Sclerosis Quality of Life (MSQOL)-54 Instrument

For Further Information, Contact:

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INSTRUCTIONS:

This survey asks about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3, ...).

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. In general, would you say your health is:
(circle one number)

- Excellent.....1
- Very good.....2
- Good.....3
- Fair.....4
- Poor.....5

2. **Compared to one year ago**, how would you rate your health in general **now**?

(circle one number)

- Much better now than one year ago..... 1
- Somewhat better now than one year ago.....2
- About the same 3
- Somewhat worse now than one year ago..... 4
- Much worse now than one year ago 5

- 3-12. The following questions are about activities you might do during a typical day. Does **your health** limit you in these activities? If so, how much?
(Circle 1, 2, or 3 on each line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
3. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing <u>several</u> flights of stairs	1	2	3
7. Climbing <u>one</u> flight of stairs	1	2	3
8. Bending, kneeling, or stooping	1	2	3
9. Walking <u>more than a mile</u>	1	2	3
10. Walking <u>several blocks</u>	1	2	3
11. Walking <u>one block</u>	1	2	3
12. Bathing and dressing yourself	1	2	3

- 13-16. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Circle one number on each line)

	YES	NO
13. Cut down on the <u>amount of time</u> you could spend on work or other activities	1	2
14. <u>Accomplished less</u> than you would like	1	2
15. Were limited in the <u>kind</u> of work or other activities	1	2
16. Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	1	2

- 17-19. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious).

(Circle one number on each line)

	YES	NO
17. Cut down on the <u>amount of time</u> you could spend on work or other activities	1	2
18. <u>Accomplished less</u> than you would like	1	2
19. Didn't do work or other activities as <u>carefully</u> as usual	1	2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one number)

- Not at all..... 1
Slightly 2
Moderately 3
Quite a bit 4
Extremely 5

Pain

21. How much **bodily** pain have you had during the **past 4 weeks**?

(circle one number)

- None 1
Very mild..... 2
Mild 3
Moderate..... 4
Severe 5
Very severe..... 6

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

(circle one number)

- Not at all..... 1
A little bit 2
Moderately 3
Quite a bit 4
Extremely..... 5

23-32. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks...** (Circle one number on each line)

	All of the Time	Most Of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6
32. Did you feel rested on waking in the morning?	1	2	3	4	5	6

33. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one number)

All of the time.....1

Most of the time.....2

Some of the time3

A little of the time.....4

None of the time5

Health in General

- 34-37. How TRUE or FALSE is each of the following statements for you.

(Circle one number on each line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
34. I seem to get sick a little easier than other people	1	2	3	4	5
35. I am as healthy as anybody I know	1	2	3	4	5
36. I expect my health to get worse	1	2	3	4	5
37. My health is excellent	1	2	3	4	5

Health Distress

How much of the time during the **past 4 weeks...**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
38. Were you discouraged by your health problems?	1	2	3	4	5	6
39. Were you frustrated about your health?	1	2	3	4	5	6
40. Was your health a worry in your life?	1	2	3	4	5	6
41. Did you feel weighed down by your health problems?	1	2	3	4	5	6

Cognitive Function

How much of the time during the **past 4 weeks...**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
42. Have you had difficulty concentrating and thinking?	1	2	3	4	5	6
43. Did you have trouble keeping your attention on an activity for long?	1	2	3	4	5	6
44. Have you had trouble with your memory?	1	2	3	4	5	6
45. Have others, such as family members or friends, noticed that you have trouble with your memory or problems with your concentration?	1	2	3	4	5	6

Sexual Function

46-50. The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function **during the last 4 weeks only.**

How much of a problem was each of the following for you **during the past 4 weeks?**

(Circle one number on each line)

MEN	Not a problem	A Little of a Problem	Somewhat of a Problem	Very Much a Problem
46. Lack of sexual interest	1	2	3	4
47. Difficulty getting or keeping an erection	1	2	3	4
48. Difficulty having orgasm	1	2	3	4
49. Ability to satisfy sexual partner	1	2	3	4

(Circle one number on each line)

WOMEN	Not a problem	A Little of a Problem	Somewhat of a Problem	Very Much a Problem
46. Lack of sexual interest	1	2	3	4
47. Inadequate lubrication	1	2	3	4
48. Difficulty having orgasm	1	2	3	4
49. Ability to satisfy sexual partner	1	2	3	4

50. Overall, how satisfied were you with your sexual function **during the past 4 weeks?**

(circle one number)

Very satisfied..... 1

Somewhat satisfied 2

Neither satisfied nor
dissatisfied 3

Somewhat dissatisfied 4

Very dissatisfied 5

51. During the **past 4 weeks**, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one number)

Not at all 1

Slightly..... 2

Moderately 3

Quite a bit..... 4

Extremely 5

52. During the **past 4 weeks**, how much did *pain* interfere with your enjoyment of life?

(circle one number)

Not at all 1

Slightly..... 2

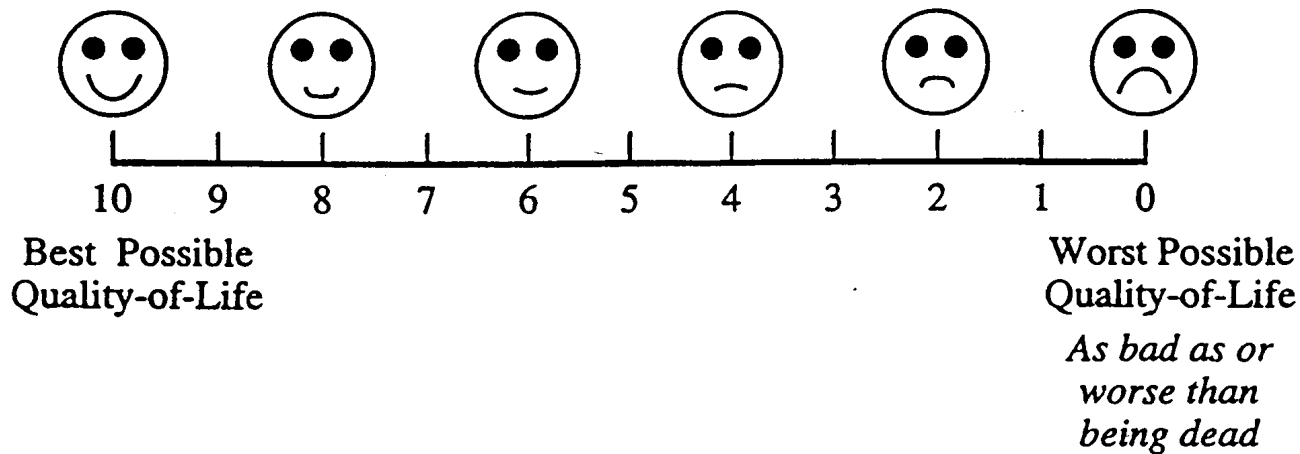
Moderately 3

Quite a bit..... 4

Extremely 5

53. Overall, how would you rate your own quality-of-life?

Circle one number on the scale below:



54. Which best describes how you feel about your life as a whole?

(circle one number)

- Terrible 1
- Unhappy 2
- Mostly dissatisfied 3
- Mixed - about equally
satisfied and dissatisfied 4
- Mostly satisfied 5
- Pleased 6
- Delighted 7

Fatigue Severity Scale (FSS)

The Fatigue Severity Scale (FSS) is a method of evaluating the impact of fatigue on you. The FSS is a short questionnaire that requires you to rate your level of fatigue.

The FSS questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.

- A low value (e.g., 1) indicates strong disagreement with the statement, whereas a high value (e.g., 7) indicates strong agreement.
- It is important that you circle a number (1 to 7) for every question.

FSS Questionnaire							
During the past week, I have found that:	Disagree <-----> Agree						
My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
Exercise brings on my fatigue.	1	2	3	4	5	6	7
I am easily fatigued.	1	2	3	4	5	6	7
Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7
	Total Score:						

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PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

ID #: _____

DATE: _____

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

add columns + +

(Healthcare professional: For interpretation of TOTAL, TOTAL:
please refer to accompanying scoring card).

10. If you checked off <i>any problems</i> , how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

Thank you for taking the time to complete the Multiple Sclerosis Questionnaire. Your involvement in this worthwhile study is greatly appreciated.

If you have any questions about the questionnaire or project please contact our research team.