



MS Priority Setting Partnership

Voting survey results

Between November 2012 and January 2013 we oversaw a large scale survey to gather questions people would like to see answered by research. The survey was completed by 507 individuals who submitted 1084 'raw' questions.

Guided by the JLA an Information Specialist and the steering group analysed all survey submissions. Questions within scope - *prevention, diagnosis, prognosis and treatment* – were grouped into topic areas and very similar questions combined into 'indicative questions'. Questions were then checked against previous research, and questions not answered by research went forward for prioritisation. At this stage the large data-set was reduced to 67 research questions.

A voting survey was launched to further reduce the 'long list' of 67 questions to a 'short list' of 30 questions, which would be used at the final workshop. Between April 2013 and May 2013, people affected by MS and healthcare professionals were invited to vote for the questions most important to them. The survey was completed by 669 people.

Results in rank order (1 = highest priority and 67 = lowest priority):

1. Which therapeutic interventions are effective for myelin repair in people with MS?
2. Which therapeutic interventions are effective to slow, stop or reverse the accumulation of disability associated with MS, including people with primary progressive (PPMS) and secondary progressive (SPMS)?
3. How can MS be prevented?
4. Which therapeutic interventions are effective to improve mobility?
5. Is stem cell therapy effective in the treatment of MS?
6. Which therapeutic interventions are effective to treat fatigue in people with MS, and which factors influence which treatments people respond to?
7. Which therapeutic interventions are effective to prevent relapses?
8. Which therapeutic interventions are effective for the treatment of pain in people with MS?
9. Is Vitamin D effective to slow, stop or reverse the accumulation of disability associated with MS?

10. Which therapeutic interventions (including cognitive rehabilitation therapies) are effective to improve cognitive function, including memory and concentration?
11. What impact does stress have on MS?
12. Is regular exercise effective in slowing, stopping, or reversing the accumulation of disability associated with MS and reducing the frequency of relapses?
13. Is regular physiotherapy effective in preventing disability in MS?
14. Does early aggressive treatment with disease modifying therapies improve prognosis of MS?
15. How can people with MS be best supported to self-manage their condition?
16. What factors influence quality of life in people with MS and are there strategies that people with MS can adapt to improve quality of life?
17. What are the side effects associated with different disease modifying drugs, including over the long-term?
18. Can MS be prevented in relatives and family members of people with MS?
19. What is the most effective and best tolerated exercise programme for people with MS?
20. Can Vitamin D prevent MS?
21. Which therapeutic interventions are effective for cerebellar ataxia (poor balance) in people with MS?
22. Is diet effective in slowing, stopping, or reversing the accumulation of disability associated with MS?
23. What is the effect of infections on disease susceptibility, relapses and progression and does treating infection have an impact on MS?
24. Is Low Dose Naltrexone (LDN) effective in slowing, stopping, or reversing the accumulation of disability associated with MS and managing the symptoms of MS?
25. Which therapeutic interventions are effective to treat spasticity in people with MS?
26. Is it possible to identify the environmental factors that could be manipulated to prevent MS?
27. Which therapeutic interventions, including catheters, are effective for people with MS to manage bladder problems?
28. Are supplements beneficial for people with MS and what supplements are most effective to treat MS?
29. What are the appropriate criteria for starting disease modifying drugs and who should prescribe them, and is this in line with guidance on reimbursement within the NHS?
30. Which therapeutic interventions are effective to treat tremors in people with MS?

31. How can quality of care by MS Nurses, in relation to diagnosis, treatment and prognosis of people with MS, be measured and improved?
32. Which therapeutic interventions are effective for people with MS to manage bowel problems?
33. How can a more accurate early diagnosis of MS be achieved?
34. Can an accurate prognosis of MS be achieved as a predictor of relapses, disability, symptoms and lifestyle changes and response to treatment?
35. Which therapeutic interventions are effective to treat depression in people with MS?
36. What impact does MS have on the ability of people with MS and carers to work and what interventions are helpful?
37. Which therapeutic interventions are effective to improve upper limb function?
38. What are the other health risks associated with MS? For example other auto immune and neurological diseases?
39. How can MRI scanning measure the progression of MS?
40. What are the palliative care needs of people with MS?
41. Can an accurate prognosis of the transition from relapse remitting MS (RRMS) to secondary progressive MS (SPMS) be achieved?
42. What is the best way to measure the progression of disability in MS?
43. Can exercise have an effect on bio-markers associated with MS?
44. Are complementary therapies effective in slowing, stopping, or reversing the accumulation of disability associated with MS?
45. What information is of value to people with MS at different stages of their condition, and for their relatives and carers? And what method of delivery is most helpful?
46. How and when can multi-disciplinary teams best advise and provide standard treatments for people with MS?
47. Can an accurate diagnosis and prognosis of primary progressive MS (PPMS) be achieved?
48. What is the most valuable structure of healthcare (care planning, involvement of MS specialists, community and practical support) for people with MS?
49. What are the effects on carers of someone with MS and how can these effects be managed?
50. Which therapeutic interventions are effective to treat burning and frozen feet in people with MS?
51. Would a vaccine to protect against Epstein Barr virus help to prevent MS?

52. What is the life expectancy of people with MS? and what are the main causes of premature death in people with MS?
53. What tools can be developed to support decision making for people with MS?
54. Which therapeutic interventions are effective to treat vertigo?
55. What impact does MS have on sexual health and which therapeutic interventions can improve this?
56. Is there professional and geographical variation within the UK in the diagnosis and treatment of MS?
57. Does supplementation of Vitamin D in pregnant women and breast feeding mothers prevent MS?
58. Is functional electrical stimulation (FES) an effective rehabilitation aid for treating foot-drop in people with MS?
59. How can progressive multifocal leukoencephalopathy (PML) be diagnosed and treated effectively in people with MS?
60. How effective is hyperbaric oxygen therapy for the treatment of MS?
61. What impact does MS have on sexual relationships and which therapeutic interventions can improve this?
62. Is cannabis an effective treatment for MS?
63. Is population screening for MS possible, available and effective for high risk groups?
64. Is treating chronic cerebrospinal venous insufficiency (CCSVI) effective for the treatment of MS?
65. Does age at diagnosis influence prognosis of MS?
66. What effect does pregnancy have on progression of MS?
67. Is the contraceptive pill effective in helping to manage MS?