

## **List of review questions for Motor Neurone Disease**

1. What factors impact upon timeliness of diagnosis in people with MND in the UK?
2. What specific MND knowledge do patients, their carers and health professionals consider is required in order to communicate diagnosis of MND, its prognosis, and choices of ongoing care appropriately?
3. What is the optimum frequency of assessing cognitive function in patients with MND?
4. A) What are the most accurate prognostic tools for estimating survival in people with MND?  
B) What risk factors predict survival in people with MND?
5. What is the most clinically and cost-effective approach for coordinating care and support across health and social care for people with MND and their families and carers?
6. What is the optimum frequency of assessment required to assess disease progression of MND?
7. What psychological support is needed for people with MND and their families and carers?
8. What are the social care support needs of people with MND and their families and carers?
9. What are the most appropriate ways of communicating with and supporting people with MND and their families and carers to help them anticipate, and prepare for, end of life?
10. For adults with MND, what is the clinical and cost-effectiveness of pharmacological treatments for muscle cramps and fasciculations, increased tone, muscle weakness, wasting or atrophy?
11. For adults with MND, what is the clinical and cost-effectiveness of non-pharmacological treatments for muscle cramps and fasciculations, increased tone (including spasticity, muscle spasm or stiffness), muscle stiffness, wasting or atrophy?
12. What is the clinical and cost-effectiveness of interventions for saliva management in people with MND?
13. What is the clinical and cost-effectiveness of cough augmentation techniques for people with MND who have an ineffective cough?
14. What are the equipment needs of people with MND for improving mobility and fulfilling activities of daily living due to muscle weakness?
15. What are the most clinically and cost-effective methods for maintaining nutritional intake and managing weight in people with MND for whom a gastrostomy is not appropriate?
16. What is the clinically appropriate timing of placement of a gastrostomy tube for nutrition management in people with MND?
17. What is the clinical and cost-effectiveness of augmentative and alternative communication systems for supporting communication in people with MND?
18. What is the clinical and cost-effectiveness of pharmacological treatments for managing breathing difficulties in people with MND?
19. What factors influenced the experience of discontinuation, at a patient's request, of NIV for relatives/carers/healthcare/social care professionals?
20. What is the most appropriate management of discontinuation, at a patient's request, of NIV?