Patient experience of MND clinics questionnaire

Date of completion _____

Please answer the following questions:

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1. Are you:

a. Male ☐ **b.** Female ☐

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2. Age

a. Under 50 ☐ **c.** 60-69 ☐

b. 51 -59 ☐ **d.** 70 + ☐

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3. Date of diagnosis?

a. Month _____ **b.** Year _____

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4. How many times have you attended the MND clinic?

a. First time ☐ **c.** Between 5 and 8 times ☐

b. Between 2 and 4 times ☐ **d.** 9 + ☐

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5. How often are you invited to attend MND clinics?

a. Every 2-3 months ☐ **b.** 6 months ☐

c. 4 months ☐ **d.** Yearly ☐

e. 5 months ☐

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6. Is the frequency of clinics appropriate for your needs?

a. Yes ☐ **c.** Mostly ☐

b. No ☐

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7. Have you ever requested an earlier clinic appointment date?

a. Yes ☐ **b.** No (please go to Q9) ☐

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8. If yes, were you offered an earlier appointment date?

a. Yes ☐ **b.** No ☐

9. Who did you see in clinic today? (Please tick all that apply)

a. Neurologist ☐
b. Palliative Care Consultan ☐
c. Respiratory consultant ☐
d. Respiratory Nurse ☐
e. MND Co-ordinator ☐
f. Physiotherapist ☐
g. Respiratory Physiotherapist ☐
h. Occupational Therapist ☐
i. Speech Therapist (SLT) ☐
j. Dietician ☐

10. Would you like to see the Respiratory Physiotherapist attending every clinic?

a. Yes ☐
b. No ☐
c. Not required currently ☐
d. Home visits are preferable ☐

11. Did you see everyone you were expecting to see today?

a. Yes (please go to Q15) ☐
b. No ☐

12. If No, were you aware the professional would not be attending today

a. Yes ☐
b. No ☐

13. If you had known, would this have influenced your decision to attend today?

a. Yes ☐
b. No ☐

14. Did this adversely affect your overall experience of attending today?

a. Yes ☐
b. No ☐

15. Is there another professional, not currently attending that you would like to see?

a. Yes ☐
b. No (please go to Q17) ☐

16. If yes, please tick all that apply

a. Dietician ☐
b. Palliative Care Nurse ☐
c. Social Worker ☐
d. Counsellor ☐
e. Benefits advisor ☐
f. Speech Therapist (SLT) ☐
g. Orthotist ☐
h. MNDA Visitor ☐
i. Other ☐

Please state _____

17. In clinic, were you able to discuss all your concerns?

a. Yes (please go to Q19) ☐ **b.** No ☐

18. If no, please state reason

a. Limited time ☐
b. High fatigue levels ☐
c. Difficulty communicating ☐
d. No rapport with professional ☐
e. Other ☐
Please state _____

19. Did you understand everything discussed today?

a. Yes ☐ **b.** No ☐

20. Do you feel your views were listened to by all professionals today?

a. Yes ☐ **b.** No ☐

21. Do you think attending the MND clinics has enabled you to manage your condition more effectively in the community?

a. Yes ☐
b. No ☐
c. Made no difference ☐

15. Please provide any additional comments you would like to make about your experiences attending MND clinics

Thank you for taking the time to give us your feedback. Your views are very important to us.