

Supplementary Table 1: Characteristics of survey participants by specialism, number

(%)*

	Consultant neurologis ts n=106	Neurology trainees n=26	Clinical genetics consultant s n=20	Genetic counsellor s n=65	MND nurses n=28
Age					
< 30	0 (0)	1 (4)	0 (0)	8 (12)	1 (4)
30 - 39	8 (8)	22 (85)	2 (10)	19 (29)	6 (21)
40 - 49	48 (45)	83 (12)	11 (55)	25 (38)	9 (32)
50 - 59	40 (38)	0 (0)	5 (25)	12 (18)	10 (36)
60 - 69	10 (9)	0 (0)	2 (10)	1 (2)	2 (7)
70 +	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Gender					
Male	64 (61)	20 (77)	9 (45)	3 (5)	4 (14)
Female	40 (38)	6 (23)	11 (55)	61 (94)	24 (86)
Non-binary	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)
Prefer not to say	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Years in substantive role					
< 5	20 (19)	18 (69)	3 (15)	16 (25)	13 (46)
5 - 9	22 (21)	8 (31)	7 (35)	10 (15)	5 (18)
10 - 14	21 (20)	0 (0)	3 (15)	19 (29)	4 (14)
15 - 19	21 (20)	0 (0)	4 (20)	7 (11)	3 (11)
20 - 24	13 (12)	0 (0)	1 (5)	5 (8)	3 (11)

25 +	9 (8)	0 (0)	2 (10)	8 (12)	0 (0)
Training in genetic counselling					
Yes	14 (13)	3 (12)	20 (100)	63 (97)	1 (4)
No	92 (87)	23 (88)	0 (0)	2 (3)	27 (96)
Special interest in MND					
Yes	34 (32)	7 (27)	8 (40)	22 (34)	28 (100)
No	72 (68)	19 (73)	12 (60)	43 (66)	0 (0)

*Percentages may not add up to 100 due to rounding

Supplementary Table 2. Neurology clinicians practice for pwMND who have a causal genetic variant.

		Discuss inheritance risk if variant identified?	Discuss predictive testing options available to relatives?	Refer to clinical genetics?
Consultant neurologist	Yes	80%	58%	82%
	Sometimes	17%	18%	16%
Neurology trainee	Yes	73%	34%	86%
	Sometimes	4%	13%	13%
MND specialist nurse	Yes	31%	25%	56%
	Sometimes	18%	25%	12%

Supplementary Table 3. Percentage of respondents self reporting as “fairly” or “very” familiar/confident per survey item.

Item	Genetic counsellors	Genetic Consultants	Neurology Consultants	Neurology Trainees	MND Specialist Nurses
Genomic testing regulations and criteria					
The National Genomic Test Directory guidance for genetic testing in MND	67%	85%	38%*	19%*	11%*
The American College of Medical Genetics criteria	75%	85%	23%*	23%*	3%*
Joint Committee on Genomics in Medicine report on Consent and Confidentiality in Genomic Medicine	91%	85%	18%*	7%*	7%*
Genetic counselling skills					
Explaining pathogenic MND gene variants	83%	95%	50%*	42%*	21%*
Explaining a	90%	90%	52%*	46%*	21%*

variant of uncertain significance					
Explaining modes of inheritance	100%	90%	78%	65%*	18%*
Explaining oligogenic inheritance	66%	85%	44%*	20%*	10%*
Explaining reduced penetrance	85%	90%	66%*	50%*	15%*
Explaining variable clinical expression	97%	90%	56%*	38%*	15%*
Explaining Genetic testing options (e.g. whole genome sequencing)	86%	90%	59%*	50%*	21%*
Reasons why people might choose these options	91%	90%	59%*	30%*	18%*
Discussing possible outcomes of testing	94%	90%	57%*	30%*	21%*

Discussing implications of a pathogenic variant being identified	98%	85%	55%*	42%*	21%*
Clinical procedures to request WGS					
Completing the 'Record of Discussion' form	94%	85%	52%*	46%*	17%*
Interpreting a genetic laboratory report	83%	85%	50%*	28%*	7%*
Communicating genetic test results to people with MND	94%	90%	55%*	35%*	7%*
Predictive testing process					
Explaining the predictive testing process	98%	85%	31%*	14%*	7%*
Explaining reasons why people might choose predictive testing or not	98%	90%	41%*	28%*	10%*

Explaining Implications of a pathogenic gene variant being identified	94%	85%	33%*	21%*	7%*
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*= $p < 0.05$ on chi-squared test. Neurology consultants and trainees compared to genetics consultants. MND specialist nurses compared to genetic counsellors.

Supplementary Table 4. Median scores on Likert-scale for each survey item for each clinician group.

Item	Genetic counsellors	Genetic Consultants	Neurology Consultants	Neurology Trainees	Specialist Nurses
Genomic testing regulations and criteria					
The National Genomic Test Directory guidance for genetic testing in MND	5 (4-5)	5 (4-5)	3 (1-4)*	3 (1-3)*	2 (1-3)**
The American College of Medical Genetics criteria	4 (3.5-5)	5 (4-5)	1 (1-3)*	2 (1-3)*	1 (1-1)**

Joint Committee on Genomics in Medicine report on Consent and Confidentiality in Genomic Medicine	5 (4-5)	5 (4-5)	1.5 (1-3)*	2 (1-3)*	1 (1-2)**
Genetic counselling skills					
Explaining pathogenic MND gene variants	4 (4-5)	5 (5-5)	3.5 (2-4)*	3 (2-4)*	1.5 (1-3)**
Explaining a variant of uncertain significance	5 (4-5)	5 (5-5)	4 (2-4)*	3 (2-4)*	1 (1-2)**
Explaining modes of inheritance	5 (4-5)	5 (5-5)	4 (4-5)*	4 (3-5)*	1 (1-2)**
Explaining oligogenic inheritance	4 (3-5)	5 (5-5)	3 (1-4)*	2 (1-3)*	1 (1-1)**
Explaining reduced penetrance	5 (4-5)	5 (5-5)	4 (3-5)*	3.5 (2-4)*	1 (1-2)**
Explaining variable clinical expression	4 (4-5)	5 (5-5)	4 (2-4.25)*	3 (2-4)*	1.5 (1-2)**
Explaining Genetic	4 (4-5)	5 (5-5)	4 (3-5)*	3.5 (2-4)*	2 (1-3)**

testing options (e.g. whole genome sequencing)					
Reasons why people might choose these options	5 (4-5)	5 (5-5)	4 (3-5)*	3 (2-4)*	2 (1-3)**
Discussing possible outcomes of testing	5 (4-5)	5 (5-5)	4 (2.75-5)*	3 (2-4)*	2 (1-3)**
Discussing implications of a pathogenic variant being identified	4 (4-5)	5 (5-5)	4 (3-5)*	3 (2-4)*	2 (2-3)**
Clinical procedures to request WGS					
Completing the 'Record of Discussion' form	5 (4-5)	5 (5-5)	4 (2-4)*	4 (1.75-4)*	2 (2-3)**
Interpreting a genetic laboratory report	4 (4-5)	5 (5-5)	4 (2-4)*	3 (2-4)*	1 (1-1.75)**
Communicating genetic test results	4 (4-5)	5 (5-5)	4 (2-5)*	3 (2-4)*	1 (1-2)**

to people with MND					
Predictive testing process					
Explaining the predictive testing process	5 (4-5)	5 (5-5)	2 (1-4)*	2 (1-3)*	1 (1-2)**
Explaining reasons why people might choose predictive testing or not	5 (4-5)	5 (5-5)	3 (1-4)*	2 (2-4)*	1 (1-2)**
Explaining Implications of a pathogenic gene variant identified	5 (4-5)	5 (5-5)	3 (1-4)*	2 (1.75-3.25)*	1 (1-2)**

* $p < 0.05$ on Wilcoxon-signed rank test. Genetics consultants compared to neurology consultants or neurology trainees.

** $p < 0.05$ on Wilcoxon-signed rank test. MND specialist nurses compared to genetic counsellors.

Supplementary Table 5. Preferred resources to support genomic testing for pwMND.

	Training resources	Local Protocols	Guidelines	Decision Aid	None of above
Neurology Consultant	65 (61%)	54 (51%)	48 (45%)	69 (65%)	6 (5%)
Neurology StR	20 (77%)	17 (66%)	18 (69%)	20 (77%)	
Specialist Nurse	26 (93%)	19 (67%)	14 (50%)	21 (75%)	

