

**Supplementary Table S1: Demographic characteristics by diagnosis**

Patient characteristics	ALS	Cerebral palsy	Guillian Barre	Metabolic Disorders	Multiple sclerosis	Diagnostic category		NMD	Neuropathy	Post-polio	Spina bifida	SMA
Total	864	8,118	1,055	1,319	36,623	Muscular dystrophy	Myasthenia gravis	94,739	1,382	< 6	3,062	30
Age (years)												
mean (SD)	71 (12)	42 (17)	57 (18)	65 (17)	47 (14)	53 (18)	53 (17)	54 (16)	62 (18)	53 (7)	41 (17)	50 (20)
Sex												
Female	354 (41)	4,016 (50)	463 (44)	657 (50)	26317 (72)	4,740 (54)	16,665 (56)	54,013 (57)	652 (47)	< 6 (60)	2026 (66)	13 (43)
Male	510 (59)	4,102 (51)	592 (56)	662 (50)	10306 (28.)	4,067 (47)	12917 (44)	40,726 (43)	730 (53)	< 6 (40)	1036 (34)	17 (57)
Neighbourhood Income Quintile												
1	194 (23)	1,976 (24)	196 (19)	286 (22)	6695 (18)	1911 (22)	5,931 (20)	17,350 (18)	310 (23)	< 6 (20)	742 (24)	11 (37)
2	183 (21)	1,667 (21)	215 (21)	307 (23)	7049 (19)	1833 (21)	6,291 (21)	18,406 (20)	282 (21)		645 (21)	6 (20)
3	175 (20)	1,545 (19)	217 (21)	269 (21)	7202 (20)	1784 (20)	6,222 (21)	18,271 (19)	251 (19)	< 6(20)	547 (18)	< 6 (13)
4	153 (18)	1,535 (19)	202 (19)	232 (18)	7567 (21)	1722 (20)	5,642 (19)	19,792 (21)	255 (19)	< 6 (40)	568 (19)	< 6 (7)
5	155 (18)	1,365 (17)	221 (21)	221 (17)	8005 (22)	1524 (17)	5,433 (18)	20,649 (22)	277 (20)	< 6 (20)	548 (18)	7 (23)
Rural Residence												
No	739 (86)	7,107 (88)	892 (85)	1,049 (80)	32,109 (88)	7549 (86)	26,787 (91)	84,751 (90)	1,163 (84)	< 6 (80)	2703 (88)	26 (87)
Yes	125 (15)	1,001 (12)	163 (16)	269 (20)	4,490 (12)	1253 (14)	2786 (9)	9,937 (11)	218 (16)	< 6 (20)	357 (12)	< 6 (13)
Immigration Status												
Citizen	812 (94)	7,619 (94)	976 (93)	1,258 (95)	34,314 (94)	8121 (92)	25,746 (87)	86,556 (91)	13,18 (95)	< 6 (100)	2752 (90)	27 (90)
Immigration	44 (5)	393 (5)	69 (7)	45 (3)	1,894 (5)	551 (6)	3,104 (11)	6,511 (7)	54 (4)	-	249 (8)	< 6 (10)
Refugee	8 (1)	106 (1)	10 (1)	16 (1)	412 (1)	135 (2)	732 (3)	1,664 (2)	10 (1)	-	61 (2)	
Comorbidity												
COPD	264 (31)	601 (7)	189 (18)	439 (33)	2,708 (7)	1247 (14)	3,521 (12)	12,599 (13)	351 (25)	< 6 (40)	234 (8)	7 (23)
Asthma	133 (15)	1068 (13)	169 (16)	226 (17)	4,861 (13)	1347 (15)	4,357 (15)	15,841 (17)	237 (17)	< 6 (20)	475 (16)	< 6 (17)
CHF	134 (16)	216 (3)	98 (9)	394 (30)	703 (2)	594 (7)	1,216 (4)	4,618 (5)	252 (18)		81 (3)	< 6 (13)
Charlson Comorbidity Index (CCI)												
0	369 (46)	1513 (65)	598 (61)	342 (27)	5,892 (72)	1378 (53)	3906 (60)	13,102 (55)	511 (42)	< 6 (40)	730 (69)	17 (59)
1 (1 to 3)	361 (45)	692 (30)	321 (33)	666 (52)	1,996 (24)	974 (37)	2194 (34)	8,862 (37)	522 (42)	< 6 (60)	270 (26)	10 (35)

2 ( $\geq 4$ )	66 (8)	114 (5)	63 (6)	273 (21)	282 (4)	258 (10)	388 (6)	1,944 (8)	197 (16)	-	55 (5)	< 6 (7)
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Note: some percentages may not sum to 100 due to rounding. ALS: amyotrophic lateral sclerosis; NMD: neuromuscular disease (other); SMA: spinal muscular atrophy; SD: standard deviation; COPD: chronic obstructive pulmonary disease; CHF: congestive heart failure.

**Supplementary Table S2: Healthcare utilization for ALS/MND and muscular dystrophy**

ALS/MND (n = 864); Muscular dystrophy (n = 8,807)	n (%) patients	Overall visits per individual	Number of visits per three years per individual <sup>b</sup>			
			2003-2005	2006-2008	2009-2011	2012-2014
Respiratory related ED visits						
ALS/MND	188 (21.76)	1.7 (1.2); 1 (1,2)	1.6 (1.1)	1.4 (0.9)	1.4 (0.8)	1.4 (0.6)
Muscular dystrophy	2173 (24.67)	2.2 (2.9); 1 (1,2)	1.6 (1.5)	1.6 (1.4)	1.6 (1.3)	1.7 (1.6)
Respiratory related hospital admission						
ALS/MND	144 (16.67)	1.4 (1); 1 (1,1)	1.3 (0.9)	1.2 (0.6)	1.4 (0.7)	1 (0)
Muscular dystrophy	1008 (11.45)	1.8 (1.8); 1 (1,2)	1.5 (0.9)	1.4 (1.1)	1.5 (1)	1.5 (1.4)
Pulmonology outpatient clinic						
ALS/MND	213 (24.7)	22 (83); 3 (1,8)	11.7 (29.7)	20.8 (58.1)	20.7 (62.2)	17 (50.1)
Muscular dystrophy	3008 (34.2)	10.9 (53.8); 3 (1,7)	6.3 (21.8)	6.1 (23.3)	7.5 (28.1)	7.5 (27.9)
Hospital pulmonology consult						
ALS/MND	147 (17)	15.8 (75.4); 3 (1,9)	9.5 (17.3)	14.2 (39.1)	22.2 (68.8)	24.8 (73.6)
Muscular dystrophy	499 (5.7)	14.7 (74.6); 3 (2,9)	10.6 (22.5)	11.5 (35.7)	12.5 (45)	12.1 (41.5)
Pulmonary function tests						
ALS/MND	144 (16.7)	2.9 (3); 2 (1,3)	2.1 (2.5)	2.5 (2)	1.9 (1.3)	2.1 (1.5)
Muscular dystrophy	3171 (36)	3.8 (6.5); 2 (1,4)	1.9 (2)	2.4 (5.2)	2.5 (3.3)	2.3 (2.2)
Sleep studies						
ALS/MND	32 (3.7)	1.5 (0.7); 1 (1,2)	1.4 (0.5)	1.4 (0.6)	1.3 (0.6)	1 (0)
Muscular dystrophy	1205 (13.7)	1.9 (1.4); 2 (1,2)	1.5 (0.6)	1.6 (1)	1.4 (0.6)	1.4 (0.6)
Outpatient clinic (non-pulmonology)						
ALS/MND	266 (30.8)	56.6 (139.4); 20.5 (5,61)	30.9 (59.6)	34.7 (74.6)	42.2 (73.7)	43.2 (74.4)
Muscular dystrophy	7864 (89.3)	84.3 (76.6); 65 (35,110)	22.1 (26)	25.8 (26.4)	30 (29.4)	28.3 (28.4)
Hospital consult (non-pulmonology)						
ALS/MND	586 (67.8)	27.5 (38.3); 15 (6,35)	20.2 (22.9)	20.1 (22.9)	18.1 (28.7)	25 (49.9)

Muscular dystrophy	914 (10.4)	21.5 (35.6); 7 (2,25)	13.8 (22.9)	13.4 (23.5)	11.5 (19.8)	12 (22.4)
All cause ED visits						
ALS/MND	513 (59.38)	5.1 (6.3); 3 (1,6)	3.3 (3.1)	3.1 (3.2)	3.7 (4.4)	4 (4.9)
Muscular dystrophy	7344 (83.39)	7.2 (17.6); 4 (2,8)	3.1 (5.0)	3.4 (7.5)	3.6 (9)	3.5 (4.9)
All cause hospital admission						
ALS/MND	496 (57.41)	2.6 (2.9); 2 (1,3)	1.9 (1.5)	1.9 (1.8)	2.05 (1.7)	2.06 (2.3)
Muscular dystrophy	4965 (56.38)	3 (3); 2 (1,4)	1.9 (1.7)	1.9 (1.6)	1.97 (1.7)	1.98 (1.6)
ICU admission						
ALS/MND	146 (16.9)	1.8 (1.7); 1 (1,2)	1.5 (1.1)	2.1 (2)	1.8 (1.5)	1.3 (0.8)
Muscular dystrophy	1692 (19.21)	1.7 (1.4); 1 (1,2)	1.6 (1.3)	1.5 (1)	1.6 (1.2)	1.6 (1.2)

a Values are mean (standard deviation); median (interquartile range) during cohort follow up.

b Calculated for individuals in the cohort requiring these services within each three-year time period.

ED: Emergency department; ICU: intensive care unit.