

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Sex; n (%)								
Female	412 (48.6%)	87 (56.5%)	165 (45.7%)	147 (49.2%)	*	-	-	9 (56.2%)
Male	435 (51.4%)	67 (43.5%)	196 (54.3%)	152 (50.8%)	9 (69.2%)	*	*	7 (43.8%)
Missing	-	-	-	-	-	-	-	-
Registry; n (%)								
BE	54 (6.4%)	5 (3.2%)	18 (5.0%)	26 (8.7%)	*	-	-	*
CZ/SK	79 (9.3%)	25 (16.2%)	17 (4.7%)	30 (10.0%)	6 (46.2%)	*	-	-
DE/AT	380 (44.9%)	80 (51.9%)	165 (45.7%)	134 (44.8%)	-	-	*	-
ES	57 (6.7%)	*	34 (9.4%)	20 (6.7%)	*	-	-	-
GB/IE	218 (25.7%)	41 (26.6%)	103 (28.5%)	60 (20.1%)	-	-	-	14 (87.5%)
SE	59 (7.0%)	*	24 (6.6%)	29 (9.7%)	*	*	-	-
Missing	-	-	-	-	-	-	-	-
Age at symptom onset (years)								
Mean (SD)	4.4 (7)	0.3 (0.3)	1 (0.9)	5.9 (6)	27.3 (9.8)	*	-	*
Median [IQR]	1.5 [0.8, 4]	0.3 [0.1, 0.5]	1 [0.6, 1]	3 [1.8, 10]	25.5 [19.2, 34.7]	*	-	*
Missing	572 (67.5%)	134 (87.0%)	257 (71.2%)	163 (54.5%)	*	-	*	14 (87.5%)
Reason for genetic testing; n (%)								
Family screening	14 (1.7%)	*	*	8 (2.7%)	*	-	-	*
Newborn screening	*	*	-	-	-	-	*	-
No screening	196 (23.1%)	5 (3.2%)	88 (24.4%)	94 (31.4%)	6 (46.2%)	*	-	-
Missing	635 (75.0%)	146 (94.8%)	272 (75.3%)	197 (65.9%)	6 (46.2%)	-	-	14 (87.5%)
Method used for genetic testing; n (%)								
ddPCR	*	-	*	*	-	-	-	-
DNA Sequencing	*	-	*	-	-	-	-	-
MLPA	109 (12.9%)	6 (3.9%)	40 (11.1%)	57 (19.1%)	*	*	-	*
qRT-PCR	*	-	-	*	-	-	-	-
RFLP	*	-	*	-	-	-	-	-

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Missing	728 (86.0%)	148 (96.1%)	318 (88.1%)	235 (78.6%)	9 (69.2%)	*	*	15 (93.8%)
SMN1 variant; n (%)								
Compound heterozygous deletion exon 7	17 (2.0%)	*	6 (1.7%)	8 (2.7%)	-	-	-	-
Homozygous deletion exon 7	710 (83.8%)	131 (85.1%)	307 (85.0%)	258 (86.3%)	9 (69.2%)	*	*	*
Missing	120 (14.2%)	20 (13.0%)	48 (13.3%)	33 (11.0%)	*	*	-	13 (81.2%)
Functional status at genetic report; n (%)								
Non-sitter	18 (2.1%)	-	9 (2.5%)	8 (2.7%)	-	-	-	*
Sitter	15 (1.8%)	-	11 (3.0%)	*	-	-	-	-
Walker	14 (1.7%)	-	*	12 (4.0%)	*	-	-	-
Missing	800 (94.5%)	154 (100.0%)	340 (94.2%)	275 (92.0%)	12 (92.3%)	*	*	15 (93.8%)
Achieved motor milestone at genetic report; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	*	-	-	*	-	-	-	-
Hold head without support	12 (1.4%)	-	*	8 (2.7%)	-	-	-	*
Roll onto side	6 (0.7%)	-	6 (1.7%)	-	-	-	-	-
Sit without support	11 (1.3%)	-	10 (2.8%)	*	-	-	-	-
Stand with assistance	*	-	*	*	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	9 (1.1%)	-	*	8 (2.7%)	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	5 (0.6%)	-	-	*	*	-	-	-
Missing	800 (94.5%)	154 (100.0%)	340 (94.2%)	275 (92.0%)	12 (92.3%)	*	*	15 (93.8%)

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Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	-	-	-
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Height (cm)								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	*	*	-	-	-	*	*	-
Median [IQR]	*	*	-	-	-	*	*	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	101.8 (9.8)	*	*	*	-	-	-	*
Median [IQR]	100 [97.2, 105]	*	*	*	-	-	-	*

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Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	129.4 (8.1)	*	*	*	-	-	-	-
Median [IQR]	129 [123.5, 131.1]	*	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	153.2 (11.1)	*	150.6 (10.4)	*	-	-	-	-
Median [IQR]	150 [145, 158.8]	*	150 [145, 151]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	163.3 (12.3)	-	157.3 (12.3)	167.2 (8.5)	*	-	-	-
Median [IQR]	165 [153, 171]	-	153.5 [150, 167.2]	167.5 [161.2, 173.2]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	161.1 (14.1)	*	154.7 (12.6)	167.9 (12.6)	-	-	-	-
Median [IQR]	163 [150, 169.5]	*	151.5 [150, 165]	168 [160.8, 178]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	162 (11.2)	-	155.6 (11.4)	166 (9.1)	-	-	-	-
Median [IQR]	162 [157, 167]	-	157 [150, 165]	164 [160, 172]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	164 (15.1)	-	156.1 (13.5)	166.4 (14.6)	*	-	-	-
Median [IQR]	166.5 [150, 175]	-	150 [146, 166.5]	168 [160.8, 175]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	166.8 (13.7)	-	148 (11.5)	169.7 (11.4)	*	-	-	-
Median [IQR]	168 [158, 178]	-	145 [140, 152]	168 [158.5, 179.5]	*	-	-	-

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Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	165.1 (8.3)	-	*	163.6 (8.5)	*	*	-	-
Median [IQR]	165.5 [158.8, 173.2]	-	*	161 [157.5, 170.5]	*	*	-	-
Missing	-	-	-	-	-	-	-	-
Weight (kg)								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	*	*	-	-	-	*	*	-
Median [IQR]	*	*	-	-	-	*	*	-
Missing	11 (78.6%)	11 (91.7%)	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	22 (95.7%)	21 (95.5%)	-	*	-	-	-	-
6 - 18 months								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	73 (97.3%)	50 (98.0%)	23 (95.8%)	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	49 (96.1%)	22 (100.0%)	25 (96.2%)	*	-	-	-	*
2 - 6 years								
Mean (SD)	*	*	*	*	-	-	-	-

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Median [IQR]	*	*	*	*	-	-	-	-
Missing	184 (97.9%)	78 (98.7%)	81 (98.8%)	22 (91.7%)	-	-	-	*
6 - 11 years								
Mean (SD)	25.4 (4.4)	*	*	*	-	-	-	-
Median [IQR]	25.8 [21, 28.9]	*	*	*	-	-	-	-
Missing	190 (96.4%)	47 (95.9%)	108 (98.2%)	33 (91.7%)	-	-	-	*
11 - 16 years								
Mean (SD)	44.5 (11)	*	*	*	-	-	-	-
Median [IQR]	42 [40.9, 47.1]	*	*	*	-	-	-	-
Missing	145 (94.8%)	12 (92.3%)	92 (95.8%)	40 (93.0%)	-	-	-	*
16 - 21 years								
Mean (SD)	50.7 (20.2)	*	41.1 (12.9)	60 (19.3)	*	-	-	-
Median [IQR]	43.6 [38, 65]	*	42 [32, 43.6]	64.5 [43.9, 65]	*	-	-	-
Missing	141 (87.0%)	7 (77.8%)	84 (90.3%)	47 (83.9%)	-	-	-	*
21 - 31 years								
Mean (SD)	56.1 (25.5)	*	51.8 (26.7)	64.3 (22.1)	-	-	-	-
Median [IQR]	52 [35.5, 71.8]	*	43 [31.8, 65.9]	66 [42, 75.5]	-	-	-	-
Missing	133 (77.3%)	*	79 (79.8%)	53 (75.7%)	-	-	-	-
31 - 41 years								
Mean (SD)	60.3 (20.7)	-	49.1 (17.6)	68.7 (18.8)	-	-	-	-
Median [IQR]	58 [49.5, 72.4]	-	50.5 [37.6, 60.5]	62 [55, 86.2]	-	-	-	-
Missing	109 (79.6%)	-	45 (78.9%)	63 (79.7%)	*	-	-	-
41 - 51 years								
Mean (SD)	58.9 (22.4)	-	*	60.5 (23.2)	-	-	-	-
Median [IQR]	58 [37, 70]	-	*	58 [41.7, 70]	-	-	-	-
Missing	84 (83.2%)	-	31 (88.6%)	51 (79.7%)	*	-	-	-
51 - 61 years								
Mean (SD)	77.2 (22.1)	-	*	79 (22.4)	*	-	-	-
Median [IQR]	73.5 [65.5, 83.8]	-	*	76 [67, 84.8]	*	-	-	-

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Missing	50 (64.1%)	-	13 (86.7%)	34 (58.6%)	*	*	-	-
> 60 years								
Mean (SD)	75.4 (18.9)	-	-	68.7 (15.5)	-	*	-	-
Median [IQR]	80 [59, 90]	-	-	65 [58.5, 82.5]	-	*	-	-
Missing	28 (75.7%)	-	*	19 (73.1%)	5 (100.0%)	-	-	*
Age at first acquisition of the best motor ability episodes								
Mean (SD)	33.9 (18.6)	3.2 (1.9)	25.8 (13.5)	38.7 (17.7)	55.5 (15.7)	-	-	*
Median [IQR]	33.2 [18.8, 47.6]	3.5 [2.1, 3.7]	24.2 [15.6, 33.4]	39.2 [23.7, 52.2]	61.8 [51.3, 63.8]	-	-	*
Missing	650 (76.7%)	149 (96.8%)	297 (82.3%)	183 (61.2%)	*	*	*	13 (81.2%)
Age at first loss of the best motor ability episodes								
Mean (SD)	36.6 (17.7)	*	29.5 (13.7)	44.8 (16.5)	*	-	-	-
Median [IQR]	34.9 [22.1, 50.8]	*	25.8 [20.7, 38.3]	46.5 [33.6, 57.3]	*	-	-	-
Missing	686 (81.0%)	150 (97.4%)	283 (78.4%)	221 (73.9%)	12 (92.3%)	*	*	16 (100.0%)
Full-time or part-time wheelchair use; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	19 (73.1%)	10 (71.4%)	9 (75.0%)	-	-	-	-	-
Yes	7 (26.9%)	*	*	-	-	-	-	-

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1.5 - 2 years								
No	24 (63.2%)	10 (71.4%)	14 (58.3%)	-	-	-	-	-
Yes	14 (36.8%)	*	10 (41.7%)	-	-	-	-	-
2 - 6 years								
No	*	-	-	*	-	-	-	-
Yes	101 (99.0%)	24 (100.0%)	67 (100.0%)	9 (90.0%)	-	-	-	*
6 - 11 years								
No	53 (34.6%)	12 (52.2%)	35 (32.4%)	5 (23.8%)	-	-	-	*
Yes	100 (65.4%)	11 (47.8%)	73 (67.6%)	16 (76.2%)	-	-	-	-
11 - 16 years								
No	74 (46.8%)	5 (41.7%)	56 (49.6%)	12 (38.7%)	-	-	-	*
Yes	84 (53.2%)	7 (58.3%)	57 (50.4%)	19 (61.3%)	-	-	-	*
16 - 21 years								
No	71 (48.6%)	5 (62.5%)	53 (51.5%)	11 (33.3%)	-	-	-	*
Yes	75 (51.4%)	*	50 (48.5%)	22 (66.7%)	-	-	-	-
21 - 31 years								
No	45 (27.8%)	*	27 (25.0%)	16 (32.0%)	-	-	-	*
Yes	117 (72.2%)	*	81 (75.0%)	34 (68.0%)	-	-	-	-
31 - 41 years								
No	38 (29.2%)	*	26 (38.8%)	11 (17.7%)	-	-	-	-
Yes	92 (70.8%)	-	41 (61.2%)	51 (82.3%)	-	-	-	-
41 - 51 years								
No	31 (31.6%)	-	11 (28.9%)	20 (33.3%)	-	-	-	-
Yes	67 (68.4%)	-	27 (71.1%)	40 (66.7%)	-	-	-	-
51 - 61 years								
No	13 (21.3%)	-	7 (41.2%)	5 (11.6%)	-	*	-	-
Yes	48 (78.7%)	-	10 (58.8%)	38 (88.4%)	-	-	-	-
> 60 years								
No	10 (27.8%)	-	*	9 (31.0%)	-	-	-	-

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Yes	26 (72.2%)	-	*	20 (69.0%)	-	*	-	*
Age at first full-time or part-time wheelchair usage (months)								
Mean (SD)	11 (14.9)	1.8 (1.3)	5.1 (8.5)	21 (16.7)	-	*	-	*
Median [IQR]	3.6 [2.4, 12]	2 [0.5, 2.5]	3 [2, 4]	13.3 [8, 33.6]	-	*	-	*
Missing	395 (46.6%)	125 (81.2%)	107 (29.6%)	134 (44.8%)	13 (100.0%)	*	*	13 (81.2%)
Number of contractures; n (%)								
< 1 month								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
1 - 3 months								
>1	-	-	-	-	-	-	-	-
0	13 (92.9%)	12 (100.0%)	-	-	-	-	*	-
1	*	-	-	-	-	*	-	-
3 - 6 months								
>1	-	-	-	-	-	-	-	-
0	23 (100.0%)	22 (100.0%)	-	*	-	-	-	-
1	-	-	-	-	-	-	-	-
6 - 18 months								
>1	-	-	-	-	-	-	-	-
0	75 (100.0%)	51 (100.0%)	24 (100.0%)	-	-	-	-	-
1	-	-	-	-	-	-	-	-
1.5 - 2 years								
>1	-	-	-	-	-	-	-	-
0	51 (100.0%)	22 (100.0%)	26 (100.0%)	*	-	-	-	*

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1	-	-	-	-	-	-	-	-
2 - 6 years								
>1	*	*	*	-	-	-	-	-
0	185 (98.4%)	78 (98.7%)	81 (98.8%)	24 (100.0%)	-	-	-	*
1	*	-	-	-	-	-	-	*
6 - 11 years								
>1	*	-	*	-	-	-	-	-
0	191 (97.0%)	49 (100.0%)	105 (95.5%)	35 (97.2%)	-	-	-	*
1	*	-	*	*	-	-	-	-
11 - 16 years								
>1	12 (7.8%)	*	7 (7.3%)	*	-	-	-	-
0	138 (90.2%)	11 (84.6%)	89 (92.7%)	37 (86.0%)	-	-	-	*
1	*	-	-	*	-	-	-	-
16 - 21 years								
>1	12 (7.4%)	*	9 (9.7%)	*	-	-	-	-
0	149 (92.0%)	8 (88.9%)	84 (90.3%)	53 (94.6%)	*	-	-	*
1	*	-	-	*	-	-	-	-
21 - 31 years								
>1	27 (15.7%)	*	21 (21.2%)	*	-	-	-	-
0	141 (82.0%)	*	76 (76.8%)	64 (91.4%)	-	-	-	-
1	*	-	*	*	-	-	-	-
31 - 41 years								
>1	21 (15.3%)	-	12 (21.1%)	9 (11.4%)	-	-	-	-
0	115 (83.9%)	-	45 (78.9%)	69 (87.3%)	*	-	-	-
1	*	-	-	*	-	-	-	-
41 - 51 years								
>1	8 (7.9%)	-	*	*	-	-	-	-
0	92 (91.1%)	-	31 (88.6%)	60 (93.8%)	*	-	-	-
1	*	-	-	-	*	-	-	-

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Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	-	*	-	-	-	*
Median [IQR]	*	-	-	*	-	-	-	*
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	*	*	-	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for RULM								
Mean (SD)	26.4 (13.6)	-	*	28.5 (11.9)	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Median [IQR]	31 [18, 37]	-	*	33 [23.2, 37]	-	-	-	-
Missing	834 (98.5%)	154 (100.0%)	360 (99.7%)	287 (96.0%)	13 (100.0%)	*	*	16 (100.0%)
Best score for RULM								
Mean (SD)	26.4 (13.6)	-	*	28.5 (11.9)	-	-	-	-
Median [IQR]	31 [18, 37]	-	*	33 [23.2, 37]	-	-	-	-
Missing	834 (98.5%)	154 (100.0%)	360 (99.7%)	287 (96.0%)	13 (100.0%)	*	*	16 (100.0%)
Most recent score for RULM								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	-	*	-	-	-	*
Median [IQR]	*	-	-	*	-	-	-	*
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Age at report of (first) best CHOP-INTEND score								
Mean (SD)	9.6 (13.2)	*	*	*	-	*	-	-
Median [IQR]	1.5 [0.2, 19.9]	*	*	*	-	*	-	-
Missing	838 (98.9%)	150 (97.4%)	358 (99.2%)	298 (99.7%)	13 (100.0%)	*	*	16 (100.0%)
Age at report of (first) best HFMS(-E) score								
Mean (SD)	28.5 (15.4)	*	*	32.2 (14.8)	-	-	-	*
Median [IQR]	26.4 [16, 42.1]	*	*	31.8 [19.1, 43.1]	-	-	-	*
Missing	828 (97.8%)	153 (99.4%)	359 (99.4%)	284 (95.0%)	13 (100.0%)	*	*	15 (93.8%)
Age at report of (first) best RULM right side score								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	846 (99.9%)	154 (100.0%)	361 (100.0%)	298 (99.7%)	13 (100.0%)	*	*	16 (100.0%)

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	7 (70.0%)	*	*	*	-	-	-	*
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	*	-	*	*	-	-	-	*
Yes	10 (71.4%)	*	6 (75.0%)	*	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	19 (100.0%)	*	12 (100.0%)	5 (100.0%)	-	-	-	-
16 - 21 years								
No	*	-	-	-	*	-	-	-
Yes	23 (95.8%)	*	16 (100.0%)	6 (100.0%)	-	-	-	-
21 - 31 years								
No	7 (11.3%)	-	-	7 (33.3%)	-	-	-	-
Yes	55 (88.7%)	*	38 (100.0%)	14 (66.7%)	-	-	-	-
31 - 41 years								
No	9 (20.0%)	-	*	8 (32.0%)	-	-	-	-
Yes	36 (80.0%)	-	19 (95.0%)	17 (68.0%)	-	-	-	-
41 - 51 years								
No	8 (27.6%)	-	-	8 (40.0%)	-	-	-	-
Yes	21 (72.4%)	-	9 (100.0%)	12 (60.0%)	-	-	-	-
51 - 61 years								
No	18 (54.5%)	-	*	14 (56.0%)	*	-	-	-
Yes	15 (45.5%)	-	*	11 (44.0%)	-	-	-	-
> 60 years								
No	10 (71.4%)	-	-	7 (77.8%)	*	-	-	-
Yes	*	-	*	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
41 - 51 years								
<30°	-	-	-	-	-	-	-	-
>45°	*	-	-	*	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
At least one use of spinal brace ever; n (%)								
No	149 (17.6%)	8 (5.2%)	63 (17.5%)	73 (24.4%)	*	*	-	-
Yes	17 (2.0%)	-	14 (3.9%)	*	-	-	-	-
Missing	681 (80.4%)	146 (94.8%)	284 (78.7%)	223 (74.6%)	10 (76.9%)	*	*	16 (100.0%)
Surgery for scoliosis; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	13 (100.0%)	12 (100.0%)	-	-	-	-	*	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
No	49 (57.6%)	-	12 (34.3%)	37 (74.0%)	-	-	-	-
Yes	36 (42.4%)	-	23 (65.7%)	13 (26.0%)	-	-	-	-
41 - 51 years								
No	35 (67.3%)	-	16 (66.7%)	19 (67.9%)	-	-	-	-
Yes	17 (32.7%)	-	8 (33.3%)	9 (32.1%)	-	-	-	-
51 - 61 years								
No	41 (93.2%)	-	6 (75.0%)	35 (97.2%)	-	-	-	-
Yes	*	-	*	*	-	-	-	-
> 60 years								
No	26 (100.0%)	-	*	21 (100.0%)	*	-	-	*
Yes	-	-	-	-	-	-	-	-
Age at surgery for scoliosis								
Mean (SD)	22.5 (19.1)	4.1 (5.3)	19.4 (14.6)	35.1 (18.8)	66.4 (5.4)	-	*	17.5 (25.4)
Median [IQR]	17.2 [5.8, 35.8]	2.2 [0.7, 4.9]	15.5 [7.1, 28.8]	35.9 [18, 49.5]	63.9 [63.8, 65.8]	-	*	6.1 [5.7, 10.4]
Missing	127 (15.0%)	29 (18.8%)	30 (8.3%)	47 (15.7%)	8 (61.5%)	*	-	10 (62.5%)
Annual number of vertebral fractures by patient reported in cause of hospitalisation or comorbidity								
Mean (SD)	-	-	-	-	*	*	-	-
Median [IQR]	-	-	-	-	*	*	-	-
Missing	750 (88.5%)	145 (94.2%)	322 (89.2%)	254 (84.9%)	11 (84.6%)	*	*	16 (100.0%)
Annual number of non-vertebral fractures by patient reported in cause of hospitalisation or comorbidity								
Mean (SD)	-	-	-	-	*	*	-	-
Median [IQR]	-	-	-	-	*	*	-	-
Missing	750 (88.5%)	145 (94.2%)	322 (89.2%)	254 (84.9%)	11 (84.6%)	*	*	16 (100.0%)

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Age at first reported vertebral fracture								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Forced vital capacity percent								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Missing	*	-	-	*	-	-	-	-
6 - 11 years								
Mean (SD)	78.7 (27.4)	-	*	*	-	-	-	-
Median [IQR]	74 [68.5, 95]	-	*	*	-	-	-	-
Missing	*	-	*	*	-	-	-	-
11 - 16 years								
Mean (SD)	47.6 (27.9)	*	33.2 (19)	*	-	-	-	-
Median [IQR]	50 [18.9, 65]	*	22 [18, 50]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	44 (34.9)	-	28.8 (23.2)	*	-	-	-	-
Median [IQR]	28 [16, 60]	-	23 [12.5, 35.5]	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
21 - 31 years								
Mean (SD)	52.2 (28.7)	-	36 (18.8)	73.1 (25.6)	-	-	-	-
Median [IQR]	46.5 [32, 65.5]	-	36 [22.2, 47.2]	73 [56.8, 97]	-	-	-	-
Missing	5 (13.5%)	*	*	*	-	-	-	-
31 - 41 years								
Mean (SD)	66.5 (28.5)	-	42.8 (20.7)	78.4 (24.1)	-	-	-	-
Median [IQR]	69.5 [44.5, 90]	-	44 [33, 48]	83.5 [65, 92.5]	-	-	-	-
Missing	6 (20.0%)	-	*	*	-	-	-	-
41 - 51 years								
Mean (SD)	73.4 (29.1)	-	53.2 (27.3)	81 (25.9)	-	-	-	-
Median [IQR]	79.7 [44.8, 98]	-	41.5 [34, 75.5]	93.5 [66, 99.5]	-	-	-	-
Missing	8 (26.7%)	-	*	*	*	-	-	-
51 - 61 years								
Mean (SD)	79.8 (29.2)	-	*	87.4 (22)	*	-	-	-
Median [IQR]	90 [55, 99]	-	*	90 [87, 99]	*	-	-	-
Missing	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Missing	*	*	-	*	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	8 (88.9%)	-	5 (100.0%)	*	-	-	-	-
11 - 16 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	12 (92.3%)	*	9 (100.0%)	*	-	-	-	-
16 - 21 years								
Mean (SD)	1.2 (1.6)	-	0.6 (0.3)	*	-	-	-	-
Median [IQR]	0.5 [0.4, 1]	-	0.4 [0.4, 0.8]	*	-	-	-	-
Missing	10 (58.8%)	-	7 (53.8%)	*	-	-	-	-
21 - 31 years								
Mean (SD)	2.2 (1.2)	*	1.5 (0.7)	2.9 (1.1)	-	-	-	-
Median [IQR]	2.1 [1.3, 2.8]	*	1.8 [0.9, 2.1]	2.7 [2.3, 4]	-	-	-	-
Missing	12 (32.4%)	-	9 (47.4%)	*	-	-	-	-
31 - 41 years								
Mean (SD)	2.4 (1.6)	-	1 (0.6)	3.2 (1.4)	-	-	-	-
Median [IQR]	2.3 [1.1, 3.7]	-	1.1 [0.4, 1.5]	3.4 [2.7, 4.2]	-	-	-	-
Missing	8 (26.7%)	-	*	*	-	-	-	-
41 - 51 years								
Mean (SD)	2.8 (1.3)	-	1.6 (0.7)	3.3 (1.3)	*	-	-	-
Median [IQR]	2.7 [1.9, 3.9]	-	2 [1.1, 2]	3.5 [2, 4.2]	*	-	-	-
Missing	10 (33.3%)	-	*	5 (26.3%)	*	-	-	-
51 - 61 years								
Mean (SD)	3.2 (1.6)	-	*	3.6 (1.2)	*	-	-	-
Median [IQR]	3.3 [2.3, 4.3]	-	*	3.7 [2.9, 4.3]	*	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	15 (93.8%)	13 (92.9%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	19 (95.0%)	14 (93.3%)	5 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	29 (78.4%)	17 (68.0%)	12 (100.0%)	-	-	-	-	-
Yes	8 (21.6%)	8 (32.0%)	-	-	-	-	-	-
6 - 11 years								
No	26 (52.0%)	9 (39.1%)	17 (63.0%)	-	-	-	-	-
Yes	24 (48.0%)	14 (60.9%)	10 (37.0%)	-	-	-	-	-
11 - 16 years								
No	32 (58.2%)	8 (53.3%)	24 (61.5%)	-	-	-	-	-
Yes	23 (41.8%)	7 (46.7%)	15 (38.5%)	*	-	-	-	-
16 - 21 years								
No	21 (32.8%)	*	16 (31.4%)	*	-	-	-	-
Yes	43 (67.2%)	8 (66.7%)	35 (68.6%)	-	-	-	-	-
21 - 31 years								
No	17 (29.8%)	*	15 (29.4%)	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Yes	40 (70.2%)	*	36 (70.6%)	*	-	-	-	-
31 - 41 years								
No	10 (33.3%)	*	8 (33.3%)	*	-	-	-	-
Yes	20 (66.7%)	-	16 (66.7%)	*	-	-	-	-
41 - 51 years								
No	11 (42.3%)	-	7 (43.8%)	*	-	-	-	-
Yes	15 (57.7%)	-	9 (56.2%)	6 (60.0%)	-	-	-	-
51 - 61 years								
No	*	-	*	*	-	-	-	-
Yes	12 (85.7%)	-	6 (85.7%)	6 (85.7%)	-	-	-	-
> 60 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	*	-	-	-	-
At least one episode of full-time non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	16 (100.0%)	14 (100.0%)	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	19 (95.0%)	14 (93.3%)	5 (100.0%)	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
At least one episode of part-time awake and sleeping non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
6 - 18 months								
No	16 (100.0%)	14 (100.0%)	*	-	-	-	-	-
1.5 - 2 years								
No	20 (100.0%)	15 (100.0%)	5 (100.0%)	-	-	-	-	-
2 - 6 years								
No	37 (100.0%)	25 (100.0%)	12 (100.0%)	-	-	-	-	-
6 - 11 years								
No	50 (100.0%)	23 (100.0%)	27 (100.0%)	-	-	-	-	-
11 - 16 years								
No	55 (100.0%)	15 (100.0%)	39 (100.0%)	*	-	-	-	-
16 - 21 years								
No	64 (100.0%)	12 (100.0%)	51 (100.0%)	*	-	-	-	-
21 - 31 years								
No	57 (100.0%)	5 (100.0%)	51 (100.0%)	*	-	-	-	-
31 - 41 years								
No	30 (100.0%)	*	24 (100.0%)	5 (100.0%)	-	-	-	-
41 - 51 years								
No	26 (100.0%)	-	16 (100.0%)	10 (100.0%)	-	-	-	-
51 - 61 years								
No	14 (100.0%)	-	7 (100.0%)	7 (100.0%)	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
> 60 years								
No	5 (100.0%)	-	*	*	-	-	-	-
At least one episode of part-time sleeping non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	15 (93.8%)	13 (92.9%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	20 (100.0%)	15 (100.0%)	5 (100.0%)	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	37 (100.0%)	25 (100.0%)	12 (100.0%)	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	50 (100.0%)	23 (100.0%)	27 (100.0%)	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	55 (100.0%)	15 (100.0%)	39 (100.0%)	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	-	-	*	-	-
3 - 6 months								
No	*	-	-	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	5 (71.4%)	*	-	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	6 (85.7%)	5 (83.3%)	-	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	6 (50.0%)	6 (50.0%)	-	-	-	-	-	-
Yes	6 (50.0%)	6 (50.0%)	-	-	-	-	-	-
6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	9 (100.0%)	9 (100.0%)	-	-	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of full-time invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	-	-	*	-	-
3 - 6 months								
No	*	-	-	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	5 (71.4%)	*	-	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	6 (85.7%)	5 (83.3%)	-	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
At least one episode of part-time awake and sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	-	-	-	-	*	-	-
3 - 6 months								
No	*	-	-	-	-	*	-	-
6 - 18 months								
No	7 (100.0%)	6 (100.0%)	-	-	-	*	-	-
1.5 - 2 years								
No	7 (100.0%)	6 (100.0%)	-	-	-	*	-	-
2 - 6 years								
No	12 (100.0%)	12 (100.0%)	-	-	-	-	-	-
6 - 11 years								
No	9 (100.0%)	9 (100.0%)	-	-	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
> 60 years								
No	*	-	-	*	-	-	-	-
At least one episode of part-time sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	-	-	-	-	*	-	-
3 - 6 months								
No	*	-	-	-	-	*	-	-
6 - 18 months								
No	7 (100.0%)	6 (100.0%)	-	-	-	*	-	-
1.5 - 2 years								
No	7 (100.0%)	6 (100.0%)	-	-	-	*	-	-
2 - 6 years								
No	12 (100.0%)	12 (100.0%)	-	-	-	-	-	-
6 - 11 years								
No	9 (100.0%)	9 (100.0%)	-	-	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
No	26 (96.3%)	23 (95.8%)	*	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	31 (100.0%)	28 (100.0%)	*	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	23 (92.0%)	20 (90.9%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	29 (93.5%)	23 (95.8%)	5 (83.3%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
11 - 16 years								
No	24 (88.9%)	10 (90.9%)	13 (86.7%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
16 - 21 years								
No	12 (63.2%)	5 (71.4%)	7 (58.3%)	-	-	-	-	-
Yes	7 (36.8%)	*	5 (41.7%)	-	-	-	-	-
21 - 31 years								
No	9 (52.9%)	*	8 (57.1%)	-	-	-	-	-
Yes	8 (47.1%)	*	6 (42.9%)	-	-	-	-	-
31 - 41 years								
No	7 (70.0%)	*	6 (66.7%)	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of exclusive feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	*	-	-	-	-	*	-	-
3 - 6 months								
No	6 (100.0%)	5 (100.0%)	-	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	26 (96.3%)	23 (95.8%)	*	-	-	*	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	31 (100.0%)	28 (100.0%)	*	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	24 (96.0%)	21 (95.5%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	29 (93.5%)	23 (95.8%)	5 (83.3%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one case of gastrostomy; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	*	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	8 (100.0%)	*	6 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	8 (100.0%)	-	5 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	27 (96.4%)	*	14 (93.3%)	11 (100.0%)	-	-	-	-
Yes	*	-	*	-	-	-	-	-
31 - 41 years								
No	12 (100.0%)	-	7 (100.0%)	5 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	19 (100.0%)	-	7 (100.0%)	12 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	21 (100.0%)	-	5 (100.0%)	14 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	7 (100.0%)	-	*	*	-	*	-	-
Yes	-	-	-	-	-	-	-	-
Age at first gastrostomy (years)								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
No	9 (52.9%)	*	5 (50.0%)	*	-	-	-	-
Yes	8 (47.1%)	-	5 (50.0%)	*	-	-	-	-
21 - 31 years								
No	8 (34.8%)	-	5 (35.7%)	*	-	-	-	-
Yes	15 (65.2%)	*	9 (64.3%)	5 (62.5%)	-	-	-	-
31 - 41 years								
No	*	-	*	*	-	-	-	-
Yes	7 (70.0%)	-	*	*	-	-	-	-
41 - 51 years								
No	6 (40.0%)	-	*	*	-	-	-	-
Yes	9 (60.0%)	-	5 (62.5%)	*	-	-	-	-
51 - 61 years								
No	*	-	*	-	-	*	-	-
Yes	6 (75.0%)	-	*	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	*	-	-
Annual number of hospitalisations								
Mean (SD)	1.3 (0.6)	1.8 (1.1)	1.2 (0.4)	1.2 (0.5)	-	*	-	-
Median [IQR]	1 [1, 1.4]	1.5 [1, 2]	1 [1, 1.4]	1 [1, 1]	-	*	-	-
Missing	799 (94.3%)	148 (96.1%)	337 (93.4%)	282 (94.3%)	13 (100.0%)	*	*	16 (100.0%)
Event-free survival (death or permanent ventilation)								
Mean (SD)	204.8 (238.8)	26.8 (31.7)	288.6 (199.7)	506.7 (217.4)	-	-	-	-
Median [IQR]	96.5 [12.2, 290.2]	11.5 [5.2, 39.8]	219 [156, 515]	532 [393.5, 588.5]	-	-	-	-
Missing	809 (95.5%)	136 (88.3%)	348 (96.4%)	292 (97.7%)	13 (100.0%)	*	*	16 (100.0%)
Causes of death - Level 1; n (%)								
A49.9 (Bacterial infection, unspecified)	*	-	*	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
J22 (Unspecified acute lower respiratory infection)	*	-	*	-	-	-	-	-
J96.0 (Acute respiratory failure)	*	*	-	-	-	-	-	-
R57.9 (Shock, unspecified)	*	-	*	-	-	-	-	-
U07.1 (COVID-19, virus identified)	*	-	*	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle accident, traffic)	*	-	-	*	-	-	-	-
Missing	840 (99.2%)	153 (99.4%)	357 (98.9%)	297 (99.3%)	13 (100.0%)	*	*	16 (100.0%)
Causes of death - Level 2; n (%)								
A49 (Bacterial infection of unspecified site)	*	-	*	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	-	*	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	*	*	-	-	-	-	-	-
R57 (Shock, not elsewhere classified)	*	-	*	-	-	-	-	-
U07 (Emergency use of U07)	*	-	*	-	-	-	-	-
V89 (Motor- or nonmotor-vehicle accident, type of vehicle unspecified)	*	-	-	*	-	-	-	-
Missing	840 (99.2%)	153 (99.4%)	357 (98.9%)	297 (99.3%)	13 (100.0%)	*	*	16 (100.0%)
Causes of death - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	*	-	*	-	-	-	-	-
J (Diseases of the respiratory system)	*	*	*	-	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	*	-	*	-	-	-	-	-
U (Codes for special purposes)	*	-	*	-	-	-	-	-
V (External causes of morbidity and mortality)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Missing	840 (99.2%)	153 (99.4%)	357 (98.9%)	297 (99.3%)	13 (100.0%)	*	*	16 (100.0%)
Causes of hospitalisation - Level 1; n (%)								
A04.7 (Enterocolitis due to Clostridium difficile)	*	-	*	-	-	-	-	-
A46.9 (Erysipelas)	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	*	-	-	*	-	-	-	-
I21.9 (Acute myocardial infarction, unspecified)	*	-	-	-	-	*	-	-
I70.2 (Atherosclerosis of arteries of extremities)	*	-	-	-	-	*	-	-
J06.9 (Acute upper respiratory infection, unspecified)	*	*	-	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	*	-	-	*	-	-	-	-
J09.9 (Influenza due to identified novel influenza A virus with other manifestations)	*	-	*	-	-	-	-	-
J12.1 (Respiratory syncytial virus pneumonia)	*	*	-	-	-	-	-	-
J15.7 (Pneumonia due to Mycoplasma pneumoniae)	*	-	-	*	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-
J69.0 (Pneumonitis due to food and vomit)	*	-	-	*	-	-	-	-
J98.7 (Respiratory infections, not elsewhere classified)	*	*	*	-	-	-	-	-
K29 (Gastritis and duodenitis)	*	-	-	*	-	-	-	-
K80.0 (Calculus of gallbladder with acute cholecystitis)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
K80.1 (Calculus of gallbladder with other cholecystitis)	*	-	-	*	-	-	-	-
K81.0 (Acute cholecystitis)	*	-	*	-	-	-	-	-
K92.9 (Disease of digestive system, unspecified)	*	-	*	*	-	-	-	-
M80 (Osteoporosis with pathological fracture)	*	*	-	-	-	-	-	-
N32.8 (Other specified disorders of bladder)	*	-	-	*	-	-	-	-
S72 (Fracture of femur)	*	-	-	*	-	-	-	-
T14.2 (Fracture of unspecified body region)	*	-	-	*	-	-	-	-
T45.0 (Antiallergic and antiemetic drugs)	*	-	-	*	-	-	-	-
T73.0 (Effects of hunger)	*	-	-	*	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 2; n (%)								
A04 (Other bacterial intestinal infections)	*	-	*	-	-	-	-	-
A46 (Erysipelas)	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	*	-	-	*	-	-	-	-
I21 (Acute myocardial infarction)	*	-	-	-	-	*	-	-
I70 (Atherosclerosis)	*	-	-	-	-	*	-	-
J06 (Acute upper respiratory infections of multiple and unspecified sites)	*	*	-	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	*	-	*	*	-	-	-	-
J12 (Viral pneumonia, not elsewhere classified)	*	*	-	-	-	-	-	-
J15 (Bacterial pneumonia, not elsewhere classified)	*	-	-	*	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
J96 (Respiratory failure, not elsewhere classified)	*	-	-	*	-	-	-	-
J98 (Other respiratory disorders)	*	*	*	-	-	-	-	-
K29 (Gastritis and duodenitis)	*	-	-	*	-	-	-	-
K80 (Cholelithiasis)	*	-	-	*	-	-	-	-
K81 (Cholecystitis)	*	-	*	-	-	-	-	-
K92 (Other diseases of digestive system)	*	-	*	*	-	-	-	-
M80 (Osteoporosis with pathological fracture)	*	*	-	-	-	-	-	-
N32 (Other disorders of bladder)	*	-	-	*	-	-	-	-
S72 (Fracture of femur)	*	-	-	*	-	-	-	-
T14 (Injury of unspecified body region)	*	-	-	*	-	-	-	-
T45 (Poisoning by primarily systemic and haematological agents, not elsewhere classified)	*	-	-	*	-	-	-	-
T73 (Effects of other deprivation)	*	-	-	*	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	*	-	*	-	-	-	-	-
B (Certain infectious and parasitic diseases)	*	-	-	*	-	-	-	-
I (Diseases of the circulatory system)	*	-	-	-	-	*	-	-
J (Diseases of the respiratory system)	10 (34.5%)	*	*	*	-	-	-	-
K (Diseases of the digestive system)	6 (20.7%)	-	*	*	-	-	-	-
M (Diseases of the musculoskeletal system and connective tissue)	*	*	-	-	-	-	-	-
N (Diseases of the genitourinary system)	*	-	-	*	-	-	-	-

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
S (Injury, poisoning and certain other consequences of external causes)	*	-	-	*	-	-	-	-
T (Injury, poisoning and certain other consequences of external causes)	*	-	-	*	-	-	-	-
missing	-	-	-	-	-	-	-	-
Incidence rate of each listed comorbidity (per patient-year)								
Diabetes	0	0	0	0	0	*	*	0
Osteoporosis	0	0	0	0	0	*	*	0
Pulmonary infections	0	0	0	0	0	*	*	0
Sleep apnea	0	0	0	0	0	*	*	0
Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Mean (SD)	49.1 (22.4)	-	60.4 (14.1)	38.6 (23.6)	-	-	-	-
Median [IQR]	50 [42, 60.6]	-	59.3 [51.5, 67.5]	43.3 [36.5, 50]	-	-	-	-
Missing	822 (97.0%)	154 (100.0%)	349 (96.7%)	286 (95.7%)	13 (100.0%)	*	*	16 (100.0%)
Best score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	47.2 (22.2)	-	59 (14.4)	36.3 (22.5)	-	-	-	-
Median [IQR]	50 [40.2, 59]	-	56.9 [51, 64.9]	42 [27.4, 50]	-	-	-	-
Missing	822 (97.0%)	154 (100.0%)	349 (96.7%)	286 (95.7%)	13 (100.0%)	*	*	16 (100.0%)
Most recent score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	49.1 (22.8)	-	60.9 (14.8)	38.2 (23.5)	-	-	-	-
Median [IQR]	53.8 [40.2, 65.4]	-	58.2 [52.4, 69]	43.3 [30.4, 54.8]	-	-	-	-
Missing	822 (97.0%)	154 (100.0%)	349 (96.7%)	286 (95.7%)	13 (100.0%)	*	*	16 (100.0%)

Never Treated SMA Type								
Indicator	Overall (N = 847)	SMA Type 1 (N = 154)	SMA Type 2 (N = 361)	SMA Type 3 (N = 299)	SMA Type 4 (N = 13)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 16)
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	-	-	-	-	-	-	*
Median [IQR]	*	-	-	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	-	*	-	-	-	*
Median [IQR]	*	-	-	*	-	-	-	*
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-7.3 (1.2)	*	-7.9 (0.5)	*	-	-	-	-
Median [IQR]	-8.1 [-8.1, -6.6]	*	-8.1 [-8.1, -8.1]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-5 (3.8)	-	-8.1 (-)	-1.8 (3)	-	-	-	-
Median [IQR]	-7.3 [-8.1, -2.7]	-	-8.1 [-8.1, -8.1]	-2.7 [-2.7, 0.2]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	-6 (3.1)	-	*	-5.4 (3.2)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Sex; n (%)								
Female	638 (48.3%)	118 (42.8%)	285 (52.8%)	220 (46.2%)	6 (66.7%)	*	*	5 (55.6%)
Male	683 (51.7%)	158 (57.2%)	255 (47.2%)	256 (53.8%)	*	*	6 (85.7%)	*
Missing	-	-	-	-	-	-	-	-
Registry; n (%)								
BE	202 (15.3%)	29 (10.5%)	83 (15.4%)	77 (16.2%)	5 (55.6%)	*	-	5 (55.6%)
CZ/SK	269 (20.4%)	71 (25.7%)	100 (18.5%)	90 (18.9%)	*	-	6 (85.7%)	-
DE/AT	302 (22.9%)	53 (19.2%)	116 (21.5%)	131 (27.5%)	*	-	-	-
ES	262 (19.8%)	70 (25.4%)	119 (22.0%)	73 (15.3%)	-	-	-	-
GB/IE	170 (12.9%)	27 (9.8%)	77 (14.3%)	63 (13.2%)	-	-	*	*
SE	116 (8.8%)	26 (9.4%)	45 (8.3%)	42 (8.8%)	-	*	-	*
Missing	-	-	-	-	-	-	-	-
Age at symptom onset (years)					23.5 (14.4)			
Mean (SD)	2.4 (4.7)	0.3 (0.8)	0.9 (0.8)	5.1 (5.9)		-	-	*
Median [IQR]	1 [0.5, 2]	0.2 [0.1, 0.3]	0.8 [0.6, 1.1]	2.5 [1.5, 6]	16 [12.8, 37]	-	-	*
Missing	120 (9.1%)	17 (6.2%)	39 (7.2%)	46 (9.7%)	*	*	7 (100.0%)	6 (66.7%)
Reason for genetic testing; n (%)								
Family screening	24 (1.8%)	*	8 (1.5%)	11 (2.3%)	-	*	-	*
Newborn screening	18 (1.4%)	7 (2.5%)	-	-	-	*	5 (71.4%)	*
No screening	701 (53.1%)	150 (54.3%)	290 (53.7%)	251 (52.7%)	7 (77.8%)	-	-	*
Prenatal screening	*	-	-	*	-	-	*	-
Missing	575 (43.5%)	116 (42.0%)	242 (44.8%)	212 (44.5%)	*	-	*	*
Method used for genetic testing; n (%)								
ddPCR	-	-	-	-	-	-	-	-
DNA Sequencing	-	-	-	-	-	-	-	-
HRM	*	-	-	*	-	-	-	-
MLPA	412 (31.2%)	80 (29.0%)	153 (28.3%)	156 (32.8%)	6 (66.7%)	*	6 (85.7%)	7 (77.8%)

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
qRT-PCR	20 (1.5%)	*	6 (1.1%)	9 (1.9%)	*	-	-	-
RFLP	*	-	*	-	-	-	-	-
Missing	884 (66.9%)	192 (69.6%)	377 (69.8%)	310 (65.1%)	*	-	*	*
SMN1 variant; n (%)								
Compound heterozygous deletion exon 7	38 (2.9%)	6 (2.2%)	14 (2.6%)	16 (3.4%)	*	-	-	*
Compound heterozygous substitutions	*	-	*	*	-	-	-	-
Homozygous deletion exon 7	1174 (88.9%)	246 (89.1%)	480 (88.9%)	424 (89.1%)	8 (88.9%)	*	6 (85.7%)	6 (66.7%)
Missing	105 (7.9%)	24 (8.7%)	43 (8.0%)	35 (7.4%)	-	-	*	*
Functional status at genetic report; n (%)								
Non-sitter	197 (14.9%)	25 (9.1%)	111 (20.6%)	59 (12.4%)	*	-	-	*
Sitter	65 (4.9%)	*	53 (9.8%)	10 (2.1%)	-	-	-	-
Walker	57 (4.3%)	-	6 (1.1%)	51 (10.7%)	-	-	-	-
Missing	1002 (75.9%)	249 (90.2%)	370 (68.5%)	356 (74.8%)	8 (88.9%)	*	7 (100.0%)	8 (88.9%)
Achieved motor milestone at genetic report; n (%)								
Climb stairs	*	-	-	*	-	-	-	-
Crawl	5 (0.4%)	*	*	*	-	-	-	-
Hold head without support	162 (12.3%)	19 (6.9%)	85 (15.7%)	56 (11.8%)	*	-	-	*
Roll onto side	35 (2.6%)	6 (2.2%)	26 (4.8%)	*	-	-	-	-
Sit without support	54 (4.1%)	*	46 (8.5%)	7 (1.5%)	-	-	-	-
Stand with assistance	*	-	*	-	-	-	-	-
Stand without assistance	*	-	*	*	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	30 (2.3%)	-	-	30 (6.3%)	-	-	-	-
Walk with assistance	5 (0.4%)	-	*	*	-	-	-	-
Walk without assistance	21 (1.6%)	-	*	17 (3.6%)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Missing	1002 (75.9%)	249 (90.2%)	370 (68.5%)	356 (74.8%)	8 (88.9%)	*	7 (100.0%)	8 (88.9%)
Best functional status; n (%)								
Non-sitter	19 (1.4%)	10 (3.6%)	7 (1.3%)	*	-	-	-	-
Sitter	*	-	*	-	-	-	-	-
Missing	1301 (98.5%)	266 (96.4%)	532 (98.5%)	474 (99.6%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Best achieved motor milestone; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	9 (0.7%)	*	6 (1.1%)	-	-	-	-	-
Roll onto side	10 (0.8%)	7 (2.5%)	*	*	-	-	-	-
Sit without support	*	-	*	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	-	-	-
Missing	1301 (98.5%)	266 (96.4%)	532 (98.5%)	474 (99.6%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Best functional status before treatment; n (%)								
Non-sitter	*	*	*	-	-	-	-	-
Sitter	15 (1.1%)	-	15 (2.8%)	-	-	-	-	-
Walker	18 (1.4%)	-	*	14 (2.9%)	*	-	-	-
Missing	1286 (97.4%)	275 (99.6%)	521 (96.5%)	462 (97.1%)	8 (88.9%)	*	7 (100.0%)	9 (100.0%)
Best functional status after treatment; n (%)								
Non-sitter	106 (8.0%)	65 (23.6%)	32 (5.9%)	7 (1.5%)	-	-	*	-
Sitter	460 (34.8%)	101 (36.6%)	329 (60.9%)	25 (5.3%)	-	*	*	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Walker	600 (45.4%)	33 (12.0%)	133 (24.6%)	418 (87.8%)	9 (100.0%)	*	*	*
Missing	155 (11.7%)	77 (27.9%)	46 (8.5%)	26 (5.5%)	-	-	*	*
Best achieved motor milestone before treatment; n (%)								
Climb stairs	8 (0.6%)	-	-	7 (1.5%)	*	-	-	-
Crawl	*	-	*	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
Roll onto side	*	*	*	-	-	-	-	-
Sit without support	10 (0.8%)	-	10 (1.9%)	-	-	-	-	-
Stand with assistance	*	-	*	-	-	-	-	-
Stand without assistance	*	-	*	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	*	-	*	*	-	-	-	-
Walk with assistance	*	-	*	-	-	-	-	-
Walk without assistance	*	-	-	*	-	-	-	-
Missing	1286 (97.4%)	275 (99.6%)	521 (96.5%)	462 (97.1%)	8 (88.9%)	*	7 (100.0%)	9 (100.0%)
Best achieved motor milestone after treatment; n (%)								
Hold head without support	41 (3.1%)	14 (5.1%)	21 (3.9%)	5 (1.1%)	-	-	*	-
Roll onto side	65 (4.9%)	51 (18.5%)	11 (2.0%)	*	-	-	*	-
Sit without support	296 (22.4%)	75 (27.2%)	205 (38.0%)	13 (2.7%)	-	*	-	*
Crawl	92 (7.0%)	6 (2.2%)	75 (13.9%)	9 (1.9%)	-	-	*	-
Stand with assistance	62 (4.7%)	20 (7.2%)	42 (7.8%)	-	-	-	-	-
Stand without assistance	10 (0.8%)	-	7 (1.3%)	*	-	-	-	-
Walk with assistance	107 (8.1%)	18 (6.5%)	86 (15.9%)	*	-	-	*	-
Walk without assistance	48 (3.6%)	8 (2.9%)	16 (3.0%)	22 (4.6%)	*	-	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Walk 10 metres without assistance	115 (8.7%)	5 (1.8%)	16 (3.0%)	92 (19.3%)	-	*	-	*
Climb stairs	330 (25.0%)	*	15 (2.8%)	302 (63.4%)	8 (88.9%)	*	-	*
Unknown	-	-	-	-	-	-	-	-
Missing	155 (11.7%)	77 (27.9%)	46 (8.5%)	26 (5.5%)	-	-	*	*
Height (cm)								
< 1 month								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	55.5 (5.4)	56.7 (3.3)	-	-	-	*	*	*
Median [IQR]	55.5 [51.8, 58.2]	56 [55, 59]	-	-	-	*	*	*
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	62.2 (3)	62 (3.1)	-	-	-	*	*	-
Median [IQR]	63 [61, 63.8]	62.2 [61, 63.6]	-	-	-	*	*	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	74.2 (4.9)	73.7 (5.4)	76.3 (2.2)	-	-	*	*	*
Median [IQR]	75 [72, 77.5]	75 [70, 76.6]	76 [75, 78]	-	-	*	*	*
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	82.1 (4.7)	82.2 (4.9)	81 (4.2)	*	-	*	-	*
Median [IQR]	81.2 [80, 85]	82 [79.4, 86]	81 [79.5, 82]	*	-	*	-	*
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	101.4 (10.4)	100.9 (11.4)	100.8 (9.2)	106.3 (9)	-	*	-	*
Median [IQR]	102 [93, 109.8]	100 [92, 110]	102.5 [93, 107]	107 [100, 113.5]	-	*	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	125.1 (18.2)	125 (10.8)	120.2 (21.9)	133 (11.6)	-	-	-	-
Median [IQR]	126 [118, 135]	125 [116.8, 133.5]	124.5 [115.5, 131.5]	133 [125.6, 140]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	151.1 (20)	148.9 (11.1)	144.4 (24.7)	158.7 (11.1)	-	-	-	*
Median [IQR]	153 [144, 162]	151.5 [142.5, 157.8]	149.5 [140, 155]	159.8 [151.8, 168]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	159.3 (18.3)	151.9 (11.7)	153.4 (21)	167.9 (10.8)	-	-	-	-
Median [IQR]	160 [150, 170]	155 [145, 160]	155 [146, 165]	170 [161, 175]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	162.8 (19)	155.6 (8.1)	153.3 (24.2)	170.6 (9.8)	*	-	-	-
Median [IQR]	164 [155, 174]	153.5 [149.5, 161.2]	159 [150, 164]	169 [163, 179]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	159.4 (20)	*	150.7 (23.7)	168.8 (9.7)	*	-	-	-
Median [IQR]	160 [150, 172]	*	155 [147, 160]	172 [163, 175]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	169.2 (12.9)	-	154.9 (12.8)	173.3 (9.7)	*	-	-	-
Median [IQR]	171 [160, 179.5]	-	159 [150, 163.8]	174.5 [165.5, 181.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	160.8 (30)	-	155.6 (13.5)	161.7 (32.9)	*	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	166 [155.2, 174.8]	-	157 [153.5, 163.8]	168 [158, 177]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	168.3 (12.6)	-	-	168.8 (13.2)	*	-	-	-
Median [IQR]	168 [159, 180]	-	-	168 [158, 182]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
Weight (kg)								
< 1 month								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	4.1 (1)	4.1 (0.6)	-	-	-	*	*	*
Median [IQR]	4 [3.7, 4.3]	4 [4, 4.5]	-	-	-	*	*	*
Missing	*	*	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	6.2 (1)	6.2 (1)	-	-	-	-	*	-
Median [IQR]	6 [5.5, 6.7]	6 [5.5, 6.8]	-	-	-	-	*	-
Missing	24 (46.2%)	22 (45.8%)	-	-	-	*	-	*
6 - 18 months								
Mean (SD)	8.6 (1.4)	8.5 (1.5)	9 (0.9)	-	-	*	*	*
Median [IQR]	8.7 [8, 9.5]	8.6 [7.8, 9]	9 [8, 9.7]	-	-	*	*	*
Missing	84 (48.6%)	67 (51.5%)	13 (41.9%)	*	-	-	*	*
1.5 - 2 years								
Mean (SD)	127.2 (1047.9)	9.9 (1.4)	405.3 (1896.4)	*	-	*	-	*
Median [IQR]	10 [9.1, 11]	10 [9.1, 10.9]	10 [9.1, 11]	*	-	*	-	*
Missing	76 (48.4%)	54 (51.9%)	21 (46.7%)	-	-	-	-	*
2 - 6 years								
Mean (SD)	21.2 (80.9)	14.8 (3.8)	29.8 (130.9)	20.8 (17)	-	*	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	15 [12.1, 17.3]	14 [12, 17]	14.8 [13, 17]	16.9 [14.8, 19.1]	-	*	-	*
Missing	174 (44.7%)	71 (41.0%)	80 (49.7%)	23 (45.1%)	-	-	-	-
6 - 11 years								
Mean (SD)	27.4 (10.4)	22.3 (6.9)	26.2 (9.8)	33.6 (10.7)	-	-	-	-
Median [IQR]	25.9 [20, 33]	20.5 [17.7, 26.6]	25 [18.1, 32]	31 [26, 40.8]	-	-	-	-
Missing	108 (38.0%)	16 (28.6%)	67 (43.5%)	25 (33.8%)	-	-	-	-
11 - 16 years								
Mean (SD)	44.2 (17.1)	32.3 (13.1)	39.5 (13.3)	52.3 (17.7)	-	-	-	*
Median [IQR]	40 [33.2, 55]	33 [22.5, 36.1]	38 [31, 48]	46.5 [38, 61.2]	-	-	-	*
Missing	103 (44.6%)	6 (30.0%)	63 (50.8%)	34 (39.5%)	-	-	-	-
16 - 21 years								
Mean (SD)	50.9 (19.2)	37.2 (17)	47.3 (19.6)	58.7 (15.7)	-	-	-	-
Median [IQR]	49.5 [38, 64.8]	36.2 [25.5, 42.5]	47.5 [34, 60]	54 [46.5, 72.6]	-	-	-	-
Missing	89 (48.6%)	5 (33.3%)	52 (53.6%)	31 (44.3%)	-	-	-	*
21 - 31 years								
Mean (SD)	56.7 (20.7)	37.4 (14.2)	48.7 (17)	69.5 (17.7)	-	-	-	-
Median [IQR]	56 [40, 72]	33.5 [25.8, 46]	49 [36.7, 59]	70 [58.5, 81.5]	-	-	-	-
Missing	80 (50.0%)	*	30 (44.8%)	45 (56.2%)	*	-	-	*
31 - 41 years								
Mean (SD)	58.9 (19.4)	*	49.3 (17.1)	72.5 (13.8)	-	-	-	-
Median [IQR]	62 [45, 71.2]	*	45 [36.5, 62.5]	70.5 [64.5, 85]	-	-	-	-
Missing	63 (56.8%)	*	20 (42.6%)	40 (66.7%)	*	-	-	-
41 - 51 years								
Mean (SD)	77.7 (20.5)	-	64 (20.9)	83 (18.5)	*	-	-	-
Median [IQR]	78 [64, 90.5]	-	63 [55.2, 80]	82.5 [66.8, 95.2]	*	-	-	-
Missing	46 (42.2%)	-	19 (54.3%)	27 (38.0%)	-	-	-	-
51 - 61 years								
Mean (SD)	71.6 (25.3)	-	61.5 (31.7)	75.2 (21.8)	*	-	-	-
Median [IQR]	68 [55, 85]	-	55 [49, 70]	74 [62, 91]	*	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
No	63 (61.8%)	45 (60.8%)	17 (63.0%)	-	-	-	-	*
Yes	39 (38.2%)	29 (39.2%)	10 (37.0%)	-	-	-	-	-
2 - 6 years								
No	13 (5.7%)	5 (5.0%)	6 (5.3%)	*	-	-	-	-
Yes	214 (94.3%)	95 (95.0%)	108 (94.7%)	10 (83.3%)	-	-	-	*
6 - 11 years								
No	19 (10.0%)	*	12 (10.5%)	*	-	-	-	-
Yes	171 (90.0%)	42 (91.3%)	102 (89.5%)	27 (90.0%)	-	-	-	-
11 - 16 years								
No	*	-	*	*	-	-	-	-
Yes	135 (97.8%)	13 (100.0%)	77 (97.5%)	45 (97.8%)	-	-	-	-
16 - 21 years								
No	6 (4.9%)	-	*	*	-	-	-	-
Yes	117 (95.1%)	11 (100.0%)	61 (95.3%)	44 (93.6%)	-	-	-	*
21 - 31 years								
No	*	-	*	*	-	-	-	-
Yes	97 (98.0%)	7 (100.0%)	51 (98.1%)	38 (97.4%)	-	-	-	*
31 - 41 years								
No	*	-	-	*	-	-	-	-
Yes	62 (98.4%)	*	38 (100.0%)	22 (95.7%)	-	-	-	-
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	54 (98.2%)	-	22 (95.7%)	31 (100.0%)	*	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	56 (100.0%)	-	15 (100.0%)	40 (100.0%)	*	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	21 (100.0%)	-	-	20 (100.0%)	*	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Age at first full-time or part-time wheelchair usage (months)								
Mean (SD)	9.1 (12.5)	2.8 (2.7)	3.9 (4.1)	19.5 (16.1)	*	-	-	*
Median [IQR]	3.5 [2, 10]	2 [2, 3]	2.8 [2, 4]	12.3 [8, 28.9]	*	-	-	*
Missing	620 (46.9%)	158 (57.2%)	194 (35.9%)	244 (51.3%)	6 (66.7%)	*	7 (100.0%)	7 (77.8%)
Number of contractures; n (%)								
< 1 month								
>1	-	-	-	-	-	-	-	-
0	*	-	-	-	-	-	*	-
1	-	-	-	-	-	-	-	-
1 - 3 months								
>1	*	*	-	-	-	-	-	-
0	19 (95.0%)	12 (92.3%)	-	-	-	*	*	*
1	-	-	-	-	-	-	-	-
3 - 6 months								
>1	6 (11.5%)	6 (12.5%)	-	-	-	-	-	-
0	45 (86.5%)	41 (85.4%)	-	-	-	*	*	*
1	*	*	-	-	-	-	-	-
6 - 18 months								
>1	14 (8.1%)	11 (8.5%)	*	-	-	-	-	-
0	150 (86.7%)	111 (85.4%)	27 (87.1%)	*	-	*	*	*
1	9 (5.2%)	8 (6.2%)	*	-	-	-	-	-
1.5 - 2 years								
>1	11 (7.0%)	8 (7.7%)	*	-	-	-	-	-
0	134 (85.4%)	88 (84.6%)	38 (84.4%)	*	-	*	-	*
1	12 (7.6%)	8 (7.7%)	*	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
6 - 18 months								
Mean (SD)	53.2 (11.7)	*	*	-	-	*	*	*
Median [IQR]	54 [46.5, 64]	*	*	-	-	*	*	*
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	52.8 (9.4)	47.2 (9.2)	56.1 (7.2)	-	-	-	-	*
Median [IQR]	53 [47, 60]	48 [38.5, 53.8]	57 [51.5, 63]	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	49.9 (11.9)	47.9 (11.3)	50.4 (12.2)	58.8 (7.8)	-	-	-	-
Median [IQR]	52.5 [41.2, 58]	51 [40.2, 56]	53 [42.5, 60.5]	64 [58, 64]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	40.7 (11.8)	*	43.2 (11.6)	-	-	-	-	-
Median [IQR]	38 [31, 49]	*	41 [38, 54]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	27.7 (15.5)	*	26 (10.7)	*	-	-	-	-
Median [IQR]	29.5 [21.5, 31.2]	*	30 [24, 31]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	27.8 (7.3)	*	26.8 (8)	*	-	-	-	-
Median [IQR]	26 [23.8, 34]	*	25 [23, 33]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	16.2 (11)	-	*	*	-	-	-	*
Median [IQR]	14.5 [8.2, 26.5]	-	*	*	-	-	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	37.2 (21.3)	*	*	-	-	-	-	-
Median [IQR]	35.5 [20, 57]	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	17.1 (12.2)	*	*	-	-	-	-	-
Median [IQR]	17 [6.5, 23.5]	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	31.4 (17.5)	19.8 (16.4)	32.6 (12.2)	50.1 (7.4)	-	*	-	*
Median [IQR]	33 [17, 46.5]	16 [6, 28.5]	37 [21, 42]	53 [50.2, 53.8]	-	*	-	*
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	31.2 (19.5)	16.7 (14.5)	24 (13.7)	53.5 (13.6)	-	-	-	-
Median [IQR]	31.5 [17.5, 41.8]	17.5 [2.5, 24.5]	22 [13, 35]	58 [52, 62]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	26.6 (25.8)	0.6 (0.7)	7.1 (8.6)	44.5 (22.1)	-	-	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	16 [4, 59]	-	4 [2, 7]	56 [21.2, 62]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	23.1 (22.2)	-	7.2 (11.3)	37.2 (19.8)	-	-	-	-
Median [IQR]	14 [3, 46.2]	-	3 [2, 8]	41 [22, 56]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	28.9 (22.7)	*	3.7 (8.3)	40.1 (16.6)	*	-	-	*
Median [IQR]	32 [2.5, 52]	*	1 [-, 2]	44.5 [26.2, 53]	*	-	-	*
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	24.8 (22.4)	*	5.1 (9.3)	35.5 (19.1)	*	-	-	-
Median [IQR]	21.5 [1.2, 42.8]	*	-	37.5 [19.8, 49.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	31 (19.5)	-	*	33.7 (18.6)	*	-	-	-
Median [IQR]	33.5 [11, 49.2]	-	*	39 [19, 50]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	29.2 (19.8)	-	*	31.3 (19.2)	*	-	-	-
Median [IQR]	39 [9.5, 47]	-	*	39 [13, 51]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for RULM								
Mean (SD)	21.9 (13.1)	10.9 (9.5)	15.2 (9.4)	30.8 (11)	34.7 (5)	-	-	*
Median [IQR]	21 [12, 33.8]	9 [5, 12]	15 [8.5, 21]	34 [24, 37]	35 [32, 37.5]	-	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Missing	971 (73.5%)	243 (88.0%)	381 (70.6%)	327 (68.7%)	*	*	7 (100.0%)	7 (77.8%)
Best score for RULM								
Mean (SD)	23.8 (12.8)	14.2 (11.4)	18 (11.1)	31.8 (9.5)	36.4 (6.1)	-	-	*
Median [IQR]	24 [14, 36]	11.5 [8.2, 19.5]	17 [10, 24]	35.5 [26.8, 37]	37 [34, 41.5]	-	-	*
Missing	967 (73.2%)	242 (87.7%)	377 (69.8%)	328 (68.9%)	*	*	7 (100.0%)	7 (77.8%)
Most recent score for RULM								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	21.4 (8.7)	14.9 (5.7)	24.1 (7.2)	31 (4.7)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	23 [13, 28]	13 [10.5, 17]	25 [21, 28.5]	34 [28, 34]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	25.3 (10.2)	14.4 (10.6)	23.1 (8)	34.8 (5.4)	-	-	-	-
Median [IQR]	27 [18.8, 34.5]	9.5 [6.2, 26.5]	24 [18.2, 28]	36 [36, 37]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	23.2 (12.4)	*	14.2 (7.4)	31.9 (8)	-	-	-	*
Median [IQR]	22 [12.5, 37]	*	12.5 [10, 18]	37 [25, 37]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	19.7 (11)	*	13.2 (7.5)	28.3 (8.2)	-	-	-	-
Median [IQR]	18.5 [11.2, 25.8]	*	13 [9, 18]	26.5 [21, 37]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	25.3 (12.6)	*	13.9 (7.8)	33 (6.1)	*	-	-	*
Median [IQR]	28 [18, 36]	*	16.5 [8, 20.2]	35 [29, 37]	*	-	-	*
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	21.3 (14.8)	*	7.6 (6.7)	32.8 (6.9)	*	-	-	-
Median [IQR]	22.5 [6, 37]	*	5 [1.5, 12.8]	32 [28.5, 37]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	30.6 (9.4)	-	*	30.9 (9.8)	*	-	-	-
Median [IQR]	33 [26, 37]	-	*	34.5 [27.2, 37]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	23.2 (13.6)	-	*	26.7 (11)	*	-	-	-
Median [IQR]	27 [13.2, 35.5]	-	*	32 [19, 37]	*	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	53.2 (21.3)	*	44.5 (15.1)	79.3 (10.4)	-	-	-	-
Median [IQR]	52 [44, 66.5]	*	49 [38.5, 53.5]	82 [80.2, 85.2]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	49.2 (27.1)	-	32.7 (10.6)	65.7 (28.5)	-	-	-	-
Median [IQR]	42 [28, 74.8]	-	36 [25.5, 39.5]	83 [43, 91.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	40.8 (22.8)	*	29.2 (12.2)	63.9 (19.9)	-	-	-	-
Median [IQR]	35 [27.5, 50.8]	*	32.5 [22.5, 34.5]	65 [46, 81]	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	55 (26.7)	-	*	*	-	-	-	-
Median [IQR]	46 [30, 83]	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for 6MWT								
Mean (SD)	320.9 (151.3)	-	*	319.6 (150.1)	318 (185.1)	-	-	*
Median [IQR]	333 [194.8, 429.2]	-	*	330 [206.2, 419.2]	320 [137.5, 501]	-	-	*
Missing	1209 (91.5%)	276 (100.0%)	539 (99.8%)	372 (78.2%)	*	*	7 (100.0%)	8 (88.9%)
Best score for 6MWT								
Mean (SD)	367.7 (153)	-	*	366.5 (152.8)	376 (177)	-	-	*
Median [IQR]	382 [273.5, 462.5]	-	*	376 [275, 458]	450 [190, 525]	-	-	*
Missing	1213 (91.8%)	276 (100.0%)	539 (99.8%)	375 (78.8%)	*	*	7 (100.0%)	8 (88.9%)

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Most recent score for 6MWT								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	227.4 (74.3)	-	-	227.4 (74.3)	-	-	-	-
Median [IQR]	251 [177, 261]	-	-	251 [177, 261]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	343.6 (156)	-	-	343.6 (156)	-	-	-	-
Median [IQR]	373 [288.2, 422.8]	-	-	373 [288.2, 422.8]	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	406.4 (133.5)	-	-	403.7 (135.6)	-	-	-	*
Median [IQR]	441 [264, 500]	-	-	435 [264, 506.8]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	370.3 (126.8)	-	-	370.3 (126.8)	-	-	-	-
Median [IQR]	359 [277.2, 453.5]	-	-	359 [277.2, 453.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	300.7 (175.2)	-	*	297.3 (173.7)	*	-	-	-
Median [IQR]	293.5 [139.8, 449]	-	*	293.5 [134.2, 441.2]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	345.1 (170.2)	-	-	341.6 (154.2)	*	-	-	-
Median [IQR]	417 [175, 482]	-	-	417 [206.5, 463.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	300.8 (154.5)	-	-	313.7 (151.9)	*	-	-	-
Median [IQR]	325 [184, 344]	-	-	333 [224.2, 345.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	331.6 (102)	-	-	355.2 (90.8)	*	-	-	-
Median [IQR]	359 [250, 426]	-	-	389.5 [322.2, 429]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-	-	-	-	-	-	-	*
Median [IQR]	-	-	-	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-	-	*	*	-	-	-	-
Median [IQR]	-	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Age at report of (first) best CHOP-INTEND score								
Mean (SD)	6.7 (8.8)	3.4 (3.3)	8.7 (8.6)	21.4 (16)	-	*	0.2 (0.2)	4.3 (6.9)
Median [IQR]	2.9 [1.7, 7.2]	2.3 [1.5, 4.3]	4.7 [2.2, 13.3]	19.7 [3.8, 28.4]	-	*	0.2 [0.1, 0.4]	1.3 [0.8, 2.3]
Missing	1083 (82.0%)	164 (59.4%)	446 (82.6%)	459 (96.4%)	9 (100.0%)	*	*	*
Age at report of (first) best HFMS(-E) score								
Mean (SD)	15.5 (13.9)	5.9 (6.6)	11.8 (9.5)	21.4 (15.5)	42.3 (10.8)	*	*	8.8 (7.4)
Median [IQR]	10.7 [5.5, 20.3]	4.1 [2.5, 5.6]	8.5 [5.3, 15.4]	16.5 [9.7, 28.8]	39.4 [38.5, 46.5]	*	*	3.6 [3.3, 14.1]
Missing	886 (67.1%)	218 (79.0%)	367 (68.0%)	284 (59.7%)	*	*	6 (85.7%)	*
Age at report of (first) best RULM right side score								
Mean (SD)	11.2 (7.2)	5.4 (3.7)	12.7 (9.1)	12 (4.3)	-	-	-	*
Median [IQR]	9.9 [5.7, 14.9]	4 [3.3, 6.1]	10.8 [5.5, 17.5]	12.5 [8.8, 14.6]	-	-	-	*
Missing	1223 (92.6%)	258 (93.5%)	500 (92.6%)	438 (92.0%)	9 (100.0%)	*	7 (100.0%)	7 (77.8%)
Age at report of (first) best HINE-2 score								
Mean (SD)	*	*	-	-	-	-	*	-
Median [IQR]	*	*	-	-	-	-	*	-
Missing	1318 (99.8%)	274 (99.3%)	540 (100.0%)	476 (100.0%)	9 (100.0%)	*	6 (85.7%)	9 (100.0%)
Age at report of (first) best MFM32 score								
Mean (SD)	17.1 (12.6)	*	14.8 (9.2)	21.2 (15.4)	-	-	-	-
Median [IQR]	13.1 [8.5, 18.3]	*	12.5 [7.6, 17]	15.5 [10.5, 25.6]	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
<30°	*	*	*	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
<30°	*	*	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
<30°	20 (57.1%)	9 (42.9%)	10 (76.9%)	*	-	-	-	-
>45°	5 (14.3%)	*	*	-	-	-	-	-
30-45°	10 (28.6%)	8 (38.1%)	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
<30°	28 (48.3%)	6 (46.2%)	16 (43.2%)	6 (75.0%)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
<30°	*	-	-	*	-		-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-
> 60 years								
<30°	-	-	-	-	-		-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-
At least one use of spinal brace ever; n (%)								
No	606 (45.9%)	88 (31.9%)	262 (48.5%)	250 (52.5%)	*	*	*	*
Yes	190 (14.4%)	89 (32.2%)	81 (15.0%)	19 (4.0%)	-	-	-	*
Missing	525 (39.7%)	99 (35.9%)	197 (36.5%)	207 (43.5%)	6 (66.7%)	*	6 (85.7%)	7 (77.8%)
Surgery for scoliosis; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	17 (100.0%)	16 (100.0%)	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	14 (100.0%)	12 (100.0%)	*	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	*	*	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	85.9 (18.5)	79 (22.1)	89 (16.5)	*	-	-	-	-
Median [IQR]	90 [72, 98.5]	78 [62.5, 98]	95 [79, 101]	*	-	-	-	-
Missing	*	*	*	-	-	-	-	-
6 - 11 years								
Mean (SD)	73.7 (29.4)	39.6 (25.8)	69.9 (21.9)	100.1 (15.8)	-	-	-	-
Median [IQR]	78 [47.8, 94]	33.5 [23, 45.8]	71 [57.5, 88]	103.5 [86.3, 113.2]	-	-	-	-
Missing	10 (11.1%)	*	6 (12.5%)	*	-	-	-	-
11 - 16 years								
Mean (SD)	66.8 (32.4)	*	46.4 (24.8)	88.1 (24.3)	-	-	-	*
Median [IQR]	63.5 [39.8, 94]	*	44 [23.8, 60.7]	92.5 [80.5, 103.3]	-	-	-	*
Missing	8 (8.3%)	*	5 (10.2%)	*	-	-	-	-
16 - 21 years								
Mean (SD)	62.4 (31.5)	*	46.1 (23.9)	83.6 (24.5)	-	-	-	-
Median [IQR]	59 [35, 93]	*	36 [30, 59]	91.5 [65.2, 97.2]	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
< 1 month								
No	*	-	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	11 (91.7%)	7 (87.5%)	-	-	-	-	*	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	13 (81.2%)	11 (78.6%)	-	-	-	-	*	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	43 (72.9%)	27 (62.8%)	11 (100.0%)	*	-	-	*	-
Yes	16 (27.1%)	16 (37.2%)	-	-	-	-	-	-
1.5 - 2 years								
No	34 (70.8%)	12 (46.2%)	18 (100.0%)	*	-	-	-	-
Yes	14 (29.2%)	14 (53.8%)	-	-	-	-	-	-
2 - 6 years								
No	99 (47.6%)	23 (22.1%)	55 (67.9%)	21 (91.3%)	-	-	-	-
Yes	109 (52.4%)	81 (77.9%)	26 (32.1%)	*	-	-	-	-
6 - 11 years								
No	75 (43.4%)	6 (18.2%)	39 (36.4%)	30 (90.9%)	-	-	-	-
Yes	98 (56.6%)	27 (81.8%)	68 (63.6%)	*	-	-	-	-
11 - 16 years								
No	72 (52.6%)	*	29 (34.9%)	39 (88.6%)	-	-	-	-
Yes	65 (47.4%)	6 (60.0%)	54 (65.1%)	5 (11.4%)	-	-	-	-
16 - 21 years								
No	55 (52.9%)	*	25 (38.5%)	29 (87.9%)	-	-	-	-
Yes	49 (47.1%)	5 (83.3%)	40 (61.5%)	*	-	-	-	-
21 - 31 years								
No	64 (62.1%)	*	18 (39.1%)	43 (93.5%)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	39 (37.9%)	8 (72.7%)	28 (60.9%)	*	-	-	-	-
31 - 41 years								
No	46 (65.7%)	*	12 (35.3%)	32 (94.1%)	-	-	-	-
Yes	24 (34.3%)	-	22 (64.7%)	*	-	-	-	-
41 - 51 years								
No	69 (85.2%)	-	13 (56.5%)	54 (96.4%)	*	-	-	-
Yes	12 (14.8%)	-	10 (43.5%)	*	-	-	-	-
51 - 61 years								
No	42 (70.0%)	-	*	37 (84.1%)	*	-	-	-
Yes	18 (30.0%)	-	11 (73.3%)	7 (15.9%)	-	-	-	-
> 60 years								
No	22 (91.7%)	-	-	21 (91.3%)	*	-	-	-
Yes	*	-	-	*	-	-	-	-
At least one episode of any non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (33.3%)	6 (33.3%)	-	-	-	-	-	-
Yes	12 (66.7%)	12 (66.7%)	-	-	-	-	-	-
3 - 6 months								
No	20 (37.0%)	19 (35.8%)	-	-	-	-	-	*
Yes	34 (63.0%)	34 (64.2%)	-	-	-	-	-	-
6 - 18 months								
No	7 (8.1%)	6 (7.1%)	*	-	-	-	-	-
Yes	79 (91.9%)	78 (92.9%)	-	-	-	-	-	*
1.5 - 2 years								
No	15 (16.9%)	13 (15.1%)	*	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	*	-	-	*	-	-	-	-
At least one episode of full-time non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	18 (100.0%)	18 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	53 (98.1%)	52 (98.1%)	-	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	82 (95.3%)	80 (95.2%)	*	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	84 (94.4%)	81 (94.2%)	*	-	-	-	-	*
Yes	5 (5.6%)	5 (5.8%)	-	-	-	-	-	-
2 - 6 years								
No	115 (95.0%)	94 (94.0%)	20 (100.0%)	-	-	-	-	*
Yes	6 (5.0%)	6 (6.0%)	-	-	-	-	-	-
6 - 11 years								
No	76 (96.2%)	29 (93.5%)	45 (97.8%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
11 - 16 years								
No	78 (98.7%)	10 (90.9%)	66 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
16 - 21 years								
No	51 (96.2%)	7 (77.8%)	44 (100.0%)	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	36 (100.0%)	9 (100.0%)	26 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	18 (94.7%)	-	17 (94.4%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	15 (93.8%)	-	8 (88.9%)	7 (100.0%)	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	18 (100.0%)	-	8 (100.0%)	10 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	18 (100.0%)	18 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	54 (100.0%)	53 (100.0%)	-	-	-	-	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
No	17 (94.4%)	-	7 (87.5%)	10 (100.0%)	-	-	-	-
Yes	*	-	*	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time sleeping non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	15 (83.3%)	15 (83.3%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	49 (90.7%)	48 (90.6%)	-	-	-	-	-	*
Yes	5 (9.3%)	5 (9.4%)	-	-	-	-	-	-
6 - 18 months								
No	76 (88.4%)	74 (88.1%)	*	-	-	-	-	*
Yes	10 (11.6%)	10 (11.9%)	-	-	-	-	-	-
1.5 - 2 years								
No	80 (89.9%)	77 (89.5%)	*	-	-	-	-	*
Yes	9 (10.1%)	9 (10.5%)	-	-	-	-	-	-
2 - 6 years								
No	106 (87.6%)	86 (86.0%)	19 (95.0%)	-	-	-	-	*
Yes	15 (12.4%)	14 (14.0%)	*	-	-	-	-	-
6 - 11 years								
No	69 (87.3%)	23 (74.2%)	44 (95.7%)	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	7 (100.0%)	*	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of full-time invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	7 (87.5%)	7 (87.5%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	11 (68.8%)	11 (68.8%)	-	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	5 (31.2%)	5 (31.2%)	-	-	-	-	-	-
1.5 - 2 years								
No	13 (68.4%)	13 (68.4%)	-	-	-	-	-	-
Yes	6 (31.6%)	6 (31.6%)	-	-	-	-	-	-
2 - 6 years								
No	21 (58.3%)	21 (58.3%)	-	-	-	-	-	-
Yes	15 (41.7%)	15 (41.7%)	-	-	-	-	-	-
6 - 11 years								
No	10 (45.5%)	8 (40.0%)	*	-	-	-	-	-
Yes	12 (54.5%)	12 (60.0%)	-	-	-	-	-	-
11 - 16 years								
No	6 (50.0%)	*	*	-	-	-	-	-
Yes	6 (50.0%)	6 (66.7%)	-	-	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time invasive ventilation episode (years)								
Mean (SD)	2.2 (3.6)	1.9 (3.6)	*	-	-	-	-	-
Median [IQR]	1 [0.5, 2.4]	0.9 [0.5, 2]	*	-	-	-	-	-
Missing	1290 (97.7%)	248 (89.9%)	537 (99.4%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Pulmonary infections reported in cause of hospitalisation or as a comorbidity; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	10 (100.0%)	7 (100.0%)	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	21 (100.0%)	17 (100.0%)	-	*	-	-	*	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	66 (95.7%)	51 (94.4%)	12 (100.0%)	*	-	*	-	*

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	46 (93.9%)	27 (90.0%)	17 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	164 (95.9%)	85 (96.6%)	60 (93.8%)	18 (100.0%)	-	-	-	*
Yes	7 (4.1%)	*	*	-	-	-	-	-
6 - 11 years								
No	123 (95.3%)	28 (96.6%)	68 (95.8%)	27 (93.1%)	-	-	-	-
Yes	6 (4.7%)	*	*	*	-	-	-	-
11 - 16 years								
No	98 (98.0%)	7 (100.0%)	54 (98.2%)	37 (97.4%)	-	-	-	-
Yes	*	-	*	*	-	-	-	-
16 - 21 years								
No	77 (100.0%)	6 (100.0%)	41 (100.0%)	30 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	50 (100.0%)	*	23 (100.0%)	24 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	37 (97.4%)	*	18 (94.7%)	18 (100.0%)	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	43 (100.0%)	-	13 (100.0%)	30 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	34 (100.0%)	-	9 (100.0%)	25 (100.0%)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	13 (100.0%)	-	-	11 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of respiratory physiotherapy; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	12 (75.0%)	12 (75.0%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	28 (77.8%)	27 (77.1%)	*	-	-	-	-	-
Yes	8 (22.2%)	8 (22.9%)	-	-	-	-	-	-
6 - 18 months								
No	40 (60.6%)	36 (58.1%)	*	-	-	-	-	-
Yes	26 (39.4%)	26 (41.9%)	-	-	-	-	-	-
1.5 - 2 years								
No	40 (55.6%)	32 (53.3%)	8 (66.7%)	-	-	-	-	-
Yes	32 (44.4%)	28 (46.7%)	*	-	-	-	-	-
2 - 6 years								
No	18 (17.3%)	10 (14.1%)	8 (25.0%)	-	-	-	-	-
Yes	86 (82.7%)	61 (85.9%)	24 (75.0%)	*	-	-	-	-
6 - 11 years								
No	14 (18.9%)	*	9 (21.4%)	*	-	-	-	-
Yes	60 (81.1%)	24 (88.9%)	33 (78.6%)	*	-	-	-	-
11 - 16 years								
No	7 (13.7%)	*	5 (12.8%)	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
No	26 (59.1%)	26 (59.1%)	-	-	-	-	-	-
Yes	18 (40.9%)	18 (40.9%)	-	-	-	-	-	-
6 - 18 months								
No	25 (36.8%)	24 (35.8%)	*	-	-	-	-	-
Yes	43 (63.2%)	43 (64.2%)	-	-	-	-	-	-
1.5 - 2 years								
No	25 (35.2%)	25 (35.7%)	-	-	-	-	-	-
Yes	46 (64.8%)	45 (64.3%)	*	-	-	-	-	-
2 - 6 years								
No	11 (14.7%)	11 (15.7%)	-	-	-	-	-	-
Yes	64 (85.3%)	59 (84.3%)	5 (100.0%)	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	21 (84.0%)	15 (78.9%)	6 (100.0%)	-	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
Yes	18 (90.0%)	5 (71.4%)	12 (100.0%)	*	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	5 (83.3%)	*	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	7 (100.0%)	*	*	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	5 (100.0%)	-	5 (100.0%)	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	*	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of exclusive feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	11 (78.6%)	11 (78.6%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	30 (68.2%)	30 (68.2%)	-	-	-	-	-	-
Yes	14 (31.8%)	14 (31.8%)	-	-	-	-	-	-
6 - 18 months								
No	33 (48.5%)	32 (47.8%)	*	-	-	-	-	-
Yes	35 (51.5%)	35 (52.2%)	-	-	-	-	-	-
1.5 - 2 years								
No	31 (43.7%)	30 (42.9%)	*	-	-	-	-	-
Yes	40 (56.3%)	40 (57.1%)	-	-	-	-	-	-
2 - 6 years								
No	28 (37.3%)	26 (37.1%)	*	-	-	-	-	-
Yes	47 (62.7%)	44 (62.9%)	*	-	-	-	-	-
6 - 11 years								
No	5 (20.0%)	5 (26.3%)	-	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	20 (80.0%)	14 (73.7%)	6 (100.0%)	-	-	-	-	-
11 - 16 years								
No	9 (45.0%)	*	5 (41.7%)	-	-	-	-	-
Yes	11 (55.0%)	*	7 (58.3%)	*	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	*	-	-	-	-
51 - 61 years								
No	*	-	*	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of supplementary feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	12 (85.7%)	12 (85.7%)	-	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	40 (90.9%)	40 (90.9%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	60 (88.2%)	59 (88.1%)	*	-	-	-	-	-
Yes	8 (11.8%)	8 (11.9%)	-	-	-	-	-	-
1.5 - 2 years								
No	65 (91.5%)	65 (92.9%)	-	-	-	-	-	-
Yes	6 (8.5%)	5 (7.1%)	*	-	-	-	-	-
2 - 6 years								
No	58 (77.3%)	55 (78.6%)	*	-	-	-	-	-
Yes	17 (22.7%)	15 (21.4%)	*	-	-	-	-	-
6 - 11 years								
No	24 (96.0%)	18 (94.7%)	6 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
11 - 16 years								
No	13 (65.0%)	5 (71.4%)	7 (58.3%)	*	-	-	-	-
Yes	7 (35.0%)	*	5 (41.7%)	-	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Age at first gastrostomy (years)								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	1321 (100.0%)	276 (100.0%)	540 (100.0%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
At least one hospitalisation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1 - 3 months								
No	10 (50.0%)	10 (58.8%)	-	-	-	-	-	-
Yes	10 (50.0%)	7 (41.2%)	-	-	-	-	*	-
3 - 6 months								
No	39 (72.2%)	36 (73.5%)	-	-	-	-	*	*
Yes	15 (27.8%)	13 (26.5%)	-	*	-	-	*	-
6 - 18 months								
No	50 (45.9%)	39 (45.3%)	8 (44.4%)	*	-	-	*	-
Yes	59 (54.1%)	47 (54.7%)	10 (55.6%)	*	-	-	-	*
1.5 - 2 years								
No	87 (66.9%)	66 (71.7%)	15 (50.0%)	*	-	-	*	*
Yes	43 (33.1%)	26 (28.3%)	15 (50.0%)	*	-	-	-	-
2 - 6 years								
No	71 (32.7%)	33 (29.7%)	28 (34.6%)	8 (36.4%)	-	-	*	*
Yes	146 (67.3%)	78 (70.3%)	53 (65.4%)	14 (63.6%)	-	-	-	*
6 - 11 years								
No	33 (22.8%)	10 (27.8%)	16 (20.8%)	7 (21.9%)	-	-	-	-
Yes	112 (77.2%)	26 (72.2%)	61 (79.2%)	25 (78.1%)	-	-	-	-
11 - 16 years								
No	26 (22.6%)	*	16 (24.6%)	7 (17.5%)	-	-	-	-

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Yes	89 (77.4%)	7 (70.0%)	49 (75.4%)	33 (82.5%)	-	-	-	-
16 - 21 years								
No	18 (22.2%)	*	10 (22.2%)	7 (23.3%)	-	-	-	-
Yes	63 (77.8%)	5 (83.3%)	35 (77.8%)	23 (76.7%)	-	-	-	-
21 - 31 years								
No	11 (22.9%)	-	6 (23.1%)	5 (25.0%)	-	-	-	-
Yes	37 (77.1%)	*	20 (76.9%)	15 (75.0%)	-	-	-	-
31 - 41 years								
No	5 (16.7%)	-	*	*	-	-	-	-
Yes	25 (83.3%)	-	15 (83.3%)	10 (83.3%)	-	-	-	-
41 - 51 years								
No	5 (14.3%)	-	*	*	-	-	-	-
Yes	30 (85.7%)	-	11 (84.6%)	19 (86.4%)	-	-	-	-
51 - 61 years								
No	*	-	*	-	-	-	-	-
Yes	23 (95.8%)	-	6 (85.7%)	17 (100.0%)	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	9 (90.0%)	-	-	7 (87.5%)	*	-	-	-
Annual number of hospitalisations								
Mean (SD)	1.6 (1)	1.7 (1.3)	1.5 (0.8)	1.6 (0.9)	*	-	*	*
Median [IQR]	1 [1, 2]	1 [1, 2]	1 [1, 2]	1 [1, 2]	*	-	*	*
Missing	802 (60.7%)	134 (48.6%)	318 (58.9%)	328 (68.9%)	7 (77.8%)	*	*	7 (77.8%)
Event-free survival (death or permanent ventilation)								
Mean (SD)	49.7 (92)	21 (37.9)	180.4 (140.2)	-	-	-	-	-
Median [IQR]	13 [6, 35]	10 [6, 24]	143 [83, 246]	-	-	-	-	-
Missing	1271 (96.2%)	235 (85.1%)	531 (98.3%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
Causes of death - Level 1; n (%)								
A49.9 (Bacterial infection, unspecified)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
R57.9 (Shock, unspecified)	-	-	-	-	-	-	-	-
R57.1 (Hypovolaemic shock)	*	*	-	-	-	-	-	-
R96.0 (Instantaneous death)	*	-	*	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle accident, traffic)	-	-	-	-	-	-	-	-
Missing	1318 (99.8%)	274 (99.3%)	539 (99.8%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Causes of death - Level 2; n (%)								
A49 (Bacterial infection of unspecified site)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
R57 (Shock, not elsewhere classified)	*	*	-	-	-	-	-	-
R96 (Other sudden death, cause unknown)	*	-	*	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
V89 (Motor- or nonmotor-vehicle accident, type of vehicle unspecified)	-	-	-	-	-	-	-	-
Missing	1318 (99.8%)	274 (99.3%)	539 (99.8%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)

Treated SMA Type								
Indicator	Overall (N = 1321)	SMA Type 1 (N = 276)	SMA Type 2 (N = 540)	SMA Type 3 (N = 476)	SMA Type 4 (N = 9)	SMA Type Other (N = 4)	SMA Type Presymptomatic (N = 7)	SMA Type Missing (N = 9)
J15.8 (Other bacterial pneumonia)	*	-	*	-	-	-	-	-
J15.9 (Bacterial pneumonia, unspecified)	*	*	*	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	*	*	-	-	-	-	-	-
J16.8 (Pneumonia due to other specified infectious organisms)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	*	-	*	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	*	*	*	-	-	-	-	-
J18.0 (Bronchopneumonia, unspecified)	12 (7.2%)	5 (7.5%)	*	5 (17.2%)	-	-	-	-
J18.9 (Pneumonia, unspecified)	*	*	-	-	-	-	-	-
J20 (Acute bronchitis)	5 (3.0%)	*	*	*	-	-	-	-
J20.9 (Acute bronchitis, unspecified)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	*	*	-	-	-	-	-	-
J21.0 (Acute bronchiolitis due to respiratory syncytial virus)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-
J35.1 (Hypertrophy of tonsils)	*	-	*	-	-	-	-	-
J35.3 (Hypertrophy of tonsils with hypertrophy of adenoids)	-	-	-	-	-	-	-	-
J69.0 (Pneumonitis due to food and vomit)	*	*	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	*	*	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	*	*	*	-	-	-	-	-

Treated SMA Type								
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M80.0 (Postmenopausal osteoporosis with pathological fracture)	*	-	-	*	-	-	-	-
M81 (Osteoporosis without pathological fracture)	*	-	*	-	-	-	-	-
M96.6 (Fracture of bone following insertion of orthopaedic implant, joint prosthesis, or bone plate)	*	-	-	-	*	-	-	-
N04 (Nephrotic syndrome)	*	-	*	-	-	-	-	-
N20.1 (Calculus of ureter)	-	-	-	-	-	-	-	-
N32.8 (Other specified disorders of bladder)	-	-	-	-	-	-	-	-
N41.2 (Abscess of prostate)	*	-	-	*	-	-	-	-
N83.2 (Other and unspecified ovarian cysts)	-	-	-	-	-	-	-	-
R00.2 (Palpitations)	*	-	*	-	-	-	-	-
R06 (Abnormalities of breathing)	*	*	-	-	-	-	-	-
R06.0 (Dyspnoea)	-	-	-	-	-	-	-	-
R09.2 (Respiratory arrest)	*	*	-	-	-	-	-	-
R11 (Nausea and vomiting)	*	-	*	-	-	-	-	-
R33 (Retention of urine)	*	-	-	*	-	-	-	-
R41.8 (Other and unspecified symptoms and signs involving cognitive functions and awareness)	*	*	-	-	-	-	-	-
R50.9 (Fever, unspecified)	*	*	*	-	-	-	-	-
R51 (Headache)	*	-	*	-	-	-	-	-
R56.0 (Febrile convulsions)	*	*	-	-	-	-	-	-
R63.3 (Feeding difficulties and mismanagement)	*	-	*	-	-	-	-	-

Treated SMA Type								
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R63.6 (Insufficient intake of food and water)	*	-	*	-	-	-	-	-
R65.2 (Systemic Inflammatory Response Syndrome of non-infectious origin without organ failure)	-	-	-	-	-	-	-	-
R73.9 (Hyperglycaemia, unspecified)	*	-	*	-	-	-	-	-
S00.9 (Superficial injury of head, part unspecified)	*	*	-	-	-	-	-	-
S36.9 (Injury of unspecified intra-abdominal organ)	*	*	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S72.0 (Fracture of neck of femur)	-	-	-	-	-	-	-	-
S72.4 (Fracture of lower end of femur)	-	-	-	-	-	-	-	-
S73.0 (Dislocation of hip)	*	-	*	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	*	-	-	*	-	-	-	-
S82.9 (Fracture of lower leg, part unspecified)	*	-	-	*	-	-	-	-
T14.2 (Fracture of unspecified body region)	10 (6.0%)	*	*	8 (27.6%)	-	-	-	-
T45.0 (Antiallergic and antiemetic drugs)	-	-	-	-	-	-	-	-
T73.0 (Effects of hunger)	-	-	-	-	-	-	-	-
T81.0 (Haemorrhage and haematoma complicating a procedure, not elsewhere classified)	*	*	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	*	-	*	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	*	-	*	-	-	-	-	-

Treated SMA Type								
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Y79.2 (Prosthetic and other implants, materials and accessory orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38.0 (Singleton, born in hospital)	-	-	-	-	-	-	-	-
Z47.8 (Other specified orthopaedic follow-up care)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 2; n (%)								
A02 (Other salmonella infections)	-	-	-	-	-	-	-	-
A04 (Other bacterial intestinal infections)	-	-	-	-	-	-	-	-
A09 (Other gastroenteritis and colitis of infectious and unspecified origin)	*	*	-	-	-	-	-	-
A46 (Erysipelas)	-	-	-	-	-	-	-	-
B34 (Viral infection of unspecified site)	-	-	-	-	-	-	-	-
B96 (Other specified bacterial agents as the cause of diseases classified to other chapters)	*	-	-	*	-	-	-	-
B97 (Viral agents as the cause of diseases classified to other chapters)	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80 (Malignant neoplasm, without specification of site)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	*	-	*	-	-	-	-	-
E08 (Diabetes mellitus due to underlying condition)	*	*	-	-	-	-	-	-
E10 (Type 1 diabetes mellitus)	*	*	-	-	-	-	-	-
E46 (Unspecified protein-energy malnutrition)	*	*	-	-	-	-	-	-

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E86 (Volume depletion)	*	*	-	-	-	-	-	-
E87 (Other disorders of fluid, electrolyte and acid-base balance)	*	-	*	-	-	-	-	-
F31 (Bipolar affective disorder)	*	-	-	*	-	-	-	-
F98 (Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence)	*	-	*	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40 (Epilepsy)	*	-	-	*	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45 (Transient cerebral ischaemic attacks and related syndromes)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	*	*	-	-	-	-	-	-
G83 (Other paralytic syndromes)	*	-	-	*	-	-	-	-
G97 (Postprocedural disorders of nervous system, not elsewhere classified)	*	-	*	-	-	-	-	-
H60 (Otitis externa)	-	-	-	-	-	-	-	-
H65 (Nonsuppurative otitis media)	*	-	*	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21 (Acute myocardial infarction)	-	-	-	-	-	-	-	-
I63 (Cerebral infarction)	-	-	-	-	-	-	-	-
I70 (Atherosclerosis)	-	-	-	-	-	-	-	-
I86 (Varicose veins of other sites)	*	-	*	-	-	-	-	-
J03 (Acute tonsillitis)	*	-	*	-	-	-	-	-

Treated SMA Type								
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J06 (Acute upper respiratory infections of multiple and unspecified sites)	10 (6.0%)	7 (10.4%)	*	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	*	*	-	-	-	-	-	-
J10 (Influenza due to identified seasonal influenza virus)	*	*	-	-	-	-	-	-
J12 (Viral pneumonia, not elsewhere classified)	5 (3.0%)	*	*	-	-	-	-	-
J15 (Bacterial pneumonia, not elsewhere classified)	9 (5.4%)	*	8 (11.6%)	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	*	*	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	*	-	*	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	17 (10.2%)	7 (10.4%)	5 (7.2%)	5 (17.2%)	-	-	-	-
J20 (Acute bronchitis)	5 (3.0%)	*	*	*	-	-	-	-
J21 (Acute bronchiolitis)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-
J35 (Chronic diseases of tonsils and adenoids)	*	-	*	-	-	-	-	-
J69 (Pneumonitis due to solids and liquids)	*	*	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	*	*	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	*	*	*	-	-	-	-	-
J98 (Other respiratory disorders)	27 (16.3%)	19 (28.4%)	8 (11.6%)	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	*	-	*	-	-	-	-	-

Treated SMA Type								
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K57 (Diverticular disease of intestine)	-	-	-	-	-	-	-	-
K59 (Other functional intestinal disorders)	-	-	-	-	-	-	-	-
K63 (Other diseases of intestine)	-	-	-	-	-	-	-	-
K71 (Toxic liver disease)	*	-	*	-	-	-	-	-
K80 (Cholelithiasis)	-	-	-	-	-	-	-	-
K81 (Cholecystitis)	-	-	-	-	-	-	-	-
K82 (Other diseases of gallbladder)	*	-	*	-	-	-	-	-
K92 (Other diseases of digestive system)	8 (4.8%)	-	*	5 (17.2%)	-	-	-	-
K94 (Complications of artificial openings of the digestive system)	*	*	-	-	-	-	-	-
M41 (Scoliosis)	*	-	*	*	-	-	-	-
M80 (Osteoporosis with pathological fracture)	*	-	-	*	-	-	-	-
M81 (Osteoporosis without pathological fracture)	*	-	*	-	-	-	-	-
M96 (Postprocedural musculoskeletal disorders, not elsewhere classified)	*	-	-	-	*	-	-	-
N04 (Nephrotic syndrome)	*	-	*	-	-	-	-	-
N20 (Calculus of kidney and ureter)	-	-	-	-	-	-	-	-
N32 (Other disorders of bladder)	-	-	-	-	-	-	-	-
N41 (Inflammatory diseases of prostate)	*	-	-	*	-	-	-	-
N83 (Noninflammatory disorders of ovary, fallopian tube and broad ligament)	-	-	-	-	-	-	-	-
R00 (Abnormalities of heart beat)	*	-	*	-	-	-	-	-
R06 (Abnormalities of breathing)	*	*	-	-	-	-	-	-

Treated SMA Type								
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T73 (Effects of other deprivation)	-	-	-	-	-	-	-	-
T81 (Complications of procedures, not elsewhere classified)	*	*	-	-	-	-	-	-
U07 (Emergency use of U07)	*	-	*	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	*	-	*	-	-	-	-	-
Y79 (Orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38 (Liveborn infants according to place of birth and type of delivery)	-	-	-	-	-	-	-	-
Z47 (Other orthopaedic follow-up care)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	*	*	-	-	-	-	-	-
B (Certain infectious and parasitic diseases)	*	-	*	*	-	-	-	-
C (Neoplasms)	-	-	-	-	-	-	-	-
D (Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism)	*	-	*	-	-	-	-	-
E (Endocrine, nutritional and metabolic diseases)	6 (3.6%)	*	*	-	-	-	-	-
F (Mental and behavioural disorders)	*	-	*	*	-	-	-	-
G (Diseases of the nervous system)	*	*	*	*	-	-	-	-
H (Diseases of the ear and mastoid process)	*	-	*	-	-	-	-	-
I (Diseases of the circulatory system)	*	-	*	-	-	-	-	-

Treated SMA Type								
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J (Diseases of the respiratory system)	90 (54.2%)	49 (73.1%)	35 (50.7%)	6 (20.7%)	-	-	-	-
K (Diseases of the digestive system)	13 (7.8%)	*	6 (8.7%)	5 (17.2%)	-	-	-	-
M (Diseases of the musculoskeletal system and connective tissue)	6 (3.6%)	-	*	*	*	-	-	-
N (Diseases of the genitourinary system)	*	-	*	*	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	17 (10.2%)	6 (9.0%)	10 (14.5%)	*	-	-	-	-
S (Injury, poisoning and certain other consequences of external causes)	5 (3.0%)	*	*	*	-	-	-	-
T (Injury, poisoning and certain other consequences of external causes)	11 (6.6%)	*	*	8 (27.6%)	-	-	-	-
U (Codes for special purposes)	*	-	*	-	-	-	-	-
W (External causes of morbidity and mortality)	*	-	*	-	-	-	-	-
Y (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Z (Factors influencing health status and contact with health services)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Incidence rate of each listed comorbidity (per patient-year)								
Diabetes	0	0	0	0	0	*	0	0
Fractures	0	0	0	0	0	*	0	0
Hepatotoxicity	0	0	0	0	0	*	0	0
Non-vertebral fractures	0	0	0	0	0	*	0	0
Osteoporosis	0	0	0	0	0	*	0	0
Pulmonary infections	0	0	0	0	0	*	0	0
Sleep apnea	0	0	0	0	0	*	0	0

Treated SMA Type								
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< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-3.7 (4.1)	*	-5.2 (2.6)	2.9 (0.9)	-	-	-	-
Median [IQR]	-4.1 [-8.1, -1.5]	*	-4.6 [-8.1, -3.2]	2.6 [2.4, 3]	-	-	-	-

Evrydsi SMA Type								
Indicator	Overall (N = 403)	SMA Type 1 (N = 64)	SMA Type 2 (N = 226)	SMA Type 3 (N = 101)	SMA Type 4 (N = 1)	SMA Type Other (N = 3)	SMA Type Presymptomatic (N = 1)	SMA Type Missing (N = 7)
Sex; n (%)								
Female	216 (53.6%)	30 (46.9%)	130 (57.5%)	48 (47.5%)	*	*	-	*
Male	187 (46.4%)	34 (53.1%)	96 (42.5%)	53 (52.5%)	-	-	*	*
Missing	-	-	-	-	-	-	-	-
Registry; n (%)								
BE	64 (15.9%)	11 (17.2%)	38 (16.8%)	9 (8.9%)	-	*	-	*
CZ/SK	73 (18.1%)	17 (26.6%)	38 (16.8%)	16 (15.8%)	*	-	*	-
DE/AT	88 (21.8%)	12 (18.8%)	46 (20.4%)	30 (29.7%)	-	-	-	-
ES	40 (9.9%)	7 (10.9%)	30 (13.3%)	*	-	-	-	-
GB/IE	82 (20.3%)	*	56 (24.8%)	20 (19.8%)	-	-	-	*
SE	56 (13.9%)	13 (20.3%)	18 (8.0%)	23 (22.8%)	-	*	-	*
Missing	-	-	-	-	-	-	-	-
Age at symptom onset (years)								
Mean (SD)	1.7 (2.8)	0.3 (0.2)	1 (0.8)	4.1 (4.6)	*	-	-	*
Median [IQR]	1 [0.5, 1.5]	0.2 [0.2, 0.4]	0.9 [0.6, 1.2]	2 [1.5, 3]	*	-	-	*
Missing	53 (13.2%)	6 (9.4%)	28 (12.4%)	11 (10.9%)	-	*	*	*
Reason for genetic testing; n (%)								
Family screening	*	-	*	-	-	*	-	-
Newborn screening	6 (1.5%)	-	-	-	-	*	*	*
No screening	216 (53.6%)	41 (64.1%)	118 (52.2%)	54 (53.5%)	*	-	-	*
Prenatal screening	-	-	-	-	-	-	-	-
Missing	177 (43.9%)	23 (35.9%)	105 (46.5%)	47 (46.5%)	-	-	-	*
Method used for genetic testing; n (%)								
ddPCR	-	-	-	-	-	-	-	-
DNA Sequencing	-	-	-	-	-	-	-	-
HRM	*	-	-	*	-	-	-	-
MLPA	155 (38.5%)	29 (45.3%)	74 (32.7%)	42 (41.6%)	*	*	*	5 (71.4%)

qRT-PCR	6 (1.5%)	*	*	-	-	-	-	-
RFLP	*	-	*	-	-	-	-	-
Missing	238 (59.1%)	33 (51.6%)	145 (64.2%)	58 (57.4%)	-	-	-	*
SMN1 variant; n (%)								
Compound heterozygous deletion exon 7	10 (2.5%)	*	6 (2.7%)	*	-	-	-	-
Compound heterozygous substitutions	*	-	*	-	-	-	-	-
Homozygous deletion exon 7	347 (86.1%)	58 (90.6%)	192 (85.0%)	87 (86.1%)	*	*	*	5 (71.4%)
Missing	44 (10.9%)	*	26 (11.5%)	12 (11.9%)	-	-	-	*
Functional status at genetic report; n (%)								
Non-sitter	70 (17.4%)	9 (14.1%)	38 (16.8%)	22 (21.8%)	-	-	-	*
Sitter	24 (6.0%)	-	22 (9.7%)	*	-	-	-	-
Walker	5 (1.2%)	-	*	*	-	-	-	-
Missing	304 (75.4%)	55 (85.9%)	164 (72.6%)	74 (73.3%)	*	*	*	6 (85.7%)
Achieved motor milestone at genetic report; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	*	-	*	*	-	-	-	-
Hold head without support	61 (15.1%)	8 (12.5%)	31 (13.7%)	21 (20.8%)	-	-	-	*
Roll onto side	9 (2.2%)	*	7 (3.1%)	*	-	-	-	-
Sit without support	20 (5.0%)	-	19 (8.4%)	*	-	-	-	-
Stand with assistance	*	-	*	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	*	-	*	*	-	-	-	-
Walk without assistance	*	-	-	*	-	-	-	-
Missing	304 (75.4%)	55 (85.9%)	164 (72.6%)	74 (73.3%)	*	*	*	6 (85.7%)
Best functional status; n (%)								

Non-sitter	10 (2.5%)	6 (9.4%)	*	*	-	-	-	-
Sitter	*	-	*	-	-	-	-	-
Missing	392 (97.3%)	58 (90.6%)	222 (98.2%)	100 (99.0%)	*	*	*	7 (100.0%)
Best achieved motor milestone; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	5 (1.2%)	*	*	-	-	-	-	-
Roll onto side	5 (1.2%)	*	*	*	-	-	-	-
Sit without support	*	-	*	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	-	-	-
Missing	392 (97.3%)	58 (90.6%)	222 (98.2%)	100 (99.0%)	*	*	*	7 (100.0%)
Best functional status before treatment; n (%)								
Non-sitter	*	*	*	-	-	-	-	-
Sitter	7 (1.7%)	-	7 (3.1%)	-	-	-	-	-
Walker	*	-	*	*	-	-	-	-
Missing	391 (97.0%)	63 (98.4%)	217 (96.0%)	99 (98.0%)	*	*	*	7 (100.0%)
Best functional status after treatment; n (%)								
Non-sitter	39 (9.7%)	19 (29.7%)	17 (7.5%)	*	-	-	*	-
Sitter	163 (40.4%)	19 (29.7%)	133 (58.8%)	8 (7.9%)	-	*	-	*
Walker	135 (33.5%)	*	45 (19.9%)	84 (83.2%)	*	*	-	*
Missing	66 (16.4%)	25 (39.1%)	31 (13.7%)	7 (6.9%)	-	-	-	*
Best achieved motor milestone before treatment; n (%)								
Climb stairs	-	-	-	-	-	-	-	-

1 - 3 months								
Mean (SD)	*	-	-	-	-	*	-	*
Median [IQR]	*	-	-	-	-	*	-	*
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	*	*	-	-	-	*	*	-
Median [IQR]	*	*	-	-	-	*	*	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	70.5 (5.3)	*	-	-	-	*	-	*
Median [IQR]	71.5 [66, 74.2]	*	-	-	-	*	-	*
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	85.2 (3.1)	*	-	-	-	-	-	*
Median [IQR]	85 [82, 87]	*	-	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	103.1 (10.5)	104.3 (12.6)	103.3 (7.3)	-	-	-	-	*
Median [IQR]	103.5 [96.4, 110]	104 [95.2, 113.8]	104 [99, 109]	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	123.2 (18.6)	123.6 (9.1)	120.3 (24)	131.3 (10)	-	-	-	-
Median [IQR]	125.5 [118, 133]	122 [117.2, 130]	128 [118, 133]	129 [125.5, 138.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	146.6 (28.5)	142.2 (11.5)	141.2 (35.7)	157.1 (7.6)	-	-	-	*
Median [IQR]	154 [146, 159]	140 [131.2, 153.2]	150.5 [141.8, 155]	157.8 [152.5, 162.1]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	156 (24.7)	*	152 (27.8)	168.5 (10.4)	-	-	-	-
Median [IQR]	160 [150, 169.5]	*	157 [150, 165]	173 [161.5, 175.5]	-	-	-	-

Mean (SD)	*	*	-	-	-	-	*	-
Median [IQR]	*	*	-	-	-	-	*	-
Missing	*	*	-	-	-	*	-	*
6 - 18 months								
Mean (SD)	8.3 (1.5)	*	-	-	-	*	-	*
Median [IQR]	8.1 [7.8, 9.2]	*	-	-	-	*	-	*
Missing	*	*	-	-	-	-	-	*
1.5 - 2 years								
Mean (SD)	9.9 (1)	*	-	-	-	-	-	*
Median [IQR]	9.3 [9.3, 10]	*	-	-	-	-	-	*
Missing	*	*	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	15.3 (3.2)	15.5 (3.5)	15.3 (3)	*	-	-	-	*
Median [IQR]	15 [12.1, 17.5]	16.1 [12.1, 17.6]	14.6 [12.6, 17.6]	*	-	-	-	*
Missing	6 (16.2%)	*	*	-	-	-	-	-
6 - 11 years								
Mean (SD)	26.3 (9.3)	22.7 (6.7)	27.8 (9.4)	30.4 (11.3)	-	-	-	-
Median [IQR]	24.3 [21, 30]	21.5 [17.1, 26.8]	25.5 [23.2, 30]	27.5 [23.4, 32.5]	-	-	-	-
Missing	12 (24.0%)	-	11 (37.9%)	*	-	-	-	-
11 - 16 years								
Mean (SD)	43.6 (16.2)	29 (19.5)	42.2 (13.9)	48 (13.4)	-	-	-	*
Median [IQR]	40.5 [32, 54]	17.6 [15, 31.3]	40 [33, 50.7]	45.1 [37.4, 57]	-	-	-	*
Missing	30 (38.0%)	*	23 (46.0%)	6 (27.3%)	-	-	-	-
16 - 21 years								
Mean (SD)	48.5 (18)	*	48.6 (18.4)	52.3 (11.2)	-	-	-	-
Median [IQR]	48.5 [34.8, 61]	*	48 [34, 60]	50.5 [43.5, 62.1]	-	-	-	-
Missing	35 (46.7%)	*	27 (51.9%)	*	-	-	-	-
21 - 31 years								
Mean (SD)	47.2 (18.3)	37.4 (14.2)	47.5 (17.2)	*	-	-	-	-
Median [IQR]	45 [33, 57]	33.5 [25.8, 46]	47.5 [35.2, 53.8]	*	-	-	-	-
Missing	21 (38.9%)	*	16 (42.1%)	*	-	-	-	-

Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	25 (100.0%)	12 (100.0%)	12 (100.0%)	-	-	-	-	*
6 - 11 years								
No	*	-	*	-	-	-	-	-
Yes	41 (95.3%)	14 (100.0%)	24 (92.3%)	*	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	47 (100.0%)	6 (100.0%)	29 (100.0%)	12 (100.0%)	-	-	-	-
16 - 21 years								
No	*	-	*	*	-	-	-	-
Yes	50 (94.3%)	5 (100.0%)	33 (97.1%)	12 (85.7%)	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	39 (100.0%)	7 (100.0%)	27 (100.0%)	5 (100.0%)	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	28 (100.0%)	*	24 (100.0%)	*	-	-	-	-
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	19 (95.0%)	-	13 (92.9%)	6 (100.0%)	-	-	-	-

>1	-	-	-	-	-	-	-	-
0	6 (85.7%)	*	-	-	-	-	-	*
1	*	*	-	-	-	-	-	-
2 - 6 years								
>1	15 (40.5%)	10 (52.6%)	5 (35.7%)	-	-	-	-	-
0	21 (56.8%)	8 (42.1%)	9 (64.3%)	*	-	-	-	*
1	*	*	-	-	-	-	-	-
6 - 11 years								
>1	28 (56.0%)	11 (78.6%)	13 (44.8%)	*	-	-	-	-
0	18 (36.0%)	*	14 (48.3%)	*	-	-	-	-
1	*	*	*	*	-	-	-	-
11 - 16 years								
>1	36 (45.6%)	*	26 (52.0%)	6 (27.3%)	-	-	-	*
0	31 (39.2%)	*	20 (40.0%)	8 (36.4%)	-	-	-	-
1	12 (15.2%)	-	*	8 (36.4%)	-	-	-	-
16 - 21 years								
>1	32 (42.7%)	*	23 (44.2%)	7 (46.7%)	-	-	-	-
0	40 (53.3%)	6 (75.0%)	28 (53.8%)	6 (40.0%)	-	-	-	-
1	*	-	*	*	-	-	-	-
21 - 31 years								
>1	25 (46.3%)	7 (70.0%)	15 (39.5%)	*	-	-	-	-
0	26 (48.1%)	*	21 (55.3%)	*	-	-	-	-
1	*	-	*	*	-	-	-	-
31 - 41 years								
>1	16 (45.7%)	-	15 (53.6%)	*	-	-	-	-
0	16 (45.7%)	*	11 (39.3%)	*	-	-	-	-
1	*	-	*	*	-	-	-	-
41 - 51 years								
>1	18 (52.9%)	-	14 (58.3%)	*	-	-	-	-
0	13 (38.2%)	-	9 (37.5%)	*	-	-	-	-
1	*	-	*	*	-	-	-	-

Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	48.8 (10.2)	50.3 (6.8)	46.6 (13.3)	-	-	-	-	-
Median [IQR]	50 [39.5, 56.5]	52 [46, 56]	40 [36, 61]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	21.6 (12)	*	25.6 (11.3)	-	-	-	-	-
Median [IQR]	30 [11.5, 31]	*	31 [30, 31]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	*	*	*	-	-	-	-
Median [IQR]	*	*	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	23.8 (11.4)	-	*	*	-	-	-	-
Median [IQR]	24 [20, 28]	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-

< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	46.8 (18.6)	-	42 (14.7)	*	-	-	-	-
Median [IQR]	50.5 [38.5, 55]	-	49 [33, 53.5]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	36.9 (15)	-	33.8 (8.5)	43.2 (21.8)	-	-	-	-
Median [IQR]	36 [25.5, 42]	-	35 [27.5, 37]	42 [25, 44]	-	-	-	-

Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	37 (12.4)	-	33.4 (9)	*	-	-	-	-
Median [IQR]	34 [30, 41.8]	-	33.5 [27.5, 36.2]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for 6MWT								
Mean (SD)	369.1 (149.1)	-	*	375.6 (154)	*	-	-	*
Median [IQR]	429.5 [260.8, 475]	-	*	436 [270.5, 481.5]	*	-	-	*
Missing	381 (94.5%)	64 (100.0%)	225 (99.6%)	82 (81.2%)	-	*	*	6 (85.7%)
Best score for 6MWT								
Mean (SD)	411.1 (141.9)	-	*	446.2 (117.8)	*	-	-	*

Median [IQR]	443 [299, 536]	-	*	485 [353, 539.8]	*	-	-	*
Missing	388 (96.3%)	64 (100.0%)	225 (99.6%)	89 (88.1%)	-	*	*	6 (85.7%)
Most recent score for 6MWT								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	305.2 (200.3)	-	-	305.2 (200.3)	-	-	-	-
Median [IQR]	311 [128.5, 494.2]	-	-	311 [128.5, 494.2]	-	-	-	-
Missing	-	-	-	-	-	-	-	-

Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-

No	8 (27.6%)	*	*	-	-	-	-	*
Yes	21 (72.4%)	14 (77.8%)	6 (85.7%)	*	-	-	-	-
6 - 11 years								
No	*	*	*	*	-	-	-	-
Yes	40 (90.9%)	9 (90.0%)	27 (93.1%)	*	-	-	-	-
11 - 16 years								
No	*	-	-	*	-	-	-	-
Yes	68 (97.1%)	5 (100.0%)	43 (100.0%)	20 (90.9%)	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	48 (100.0%)	*	38 (100.0%)	7 (100.0%)	-	-	-	-
21 - 31 years								
No	*	*	*	-	-	-	-	-
Yes	42 (95.5%)	9 (90.0%)	26 (96.3%)	7 (100.0%)	-	-	-	-
31 - 41 years								
No	*	-	-	*	-	-	-	-
Yes	30 (90.9%)	*	27 (100.0%)	*	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	25 (86.2%)	-	20 (100.0%)	5 (55.6%)	-	-	-	-
51 - 61 years								
No	7 (26.9%)	-	-	7 (46.7%)	-	-	-	-
Yes	19 (73.1%)	-	10 (100.0%)	8 (53.3%)	*	-	-	-
> 60 years								
No	6 (66.7%)	-	-	6 (66.7%)	-	-	-	-
Yes	*	-	-	*	-	-	-	-
Cobb angle value; n (%)								
< 1 month								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-

30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
<30°	*	*	*	-	-	-	-	-
>45°	*	*	*	-	-	-	-	-
30-45°	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
<30°	11 (64.7%)	*	6 (54.5%)	*	-	-	-	-
>45°	*	-	*	-	-	-	-	-
30-45°	*	*	*	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
11 - 16 years								
<30°	6 (18.2%)	*	*	*	-	-	-	-
>45°	24 (72.7%)	*	16 (80.0%)	7 (63.6%)	-	-	-	-
30-45°	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
<30°	*	-	*	*	-	-	-	-
>45°	8 (57.1%)	*	*	5 (62.5%)	-	-	-	-
30-45°	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
<30°	-	-	-	-	-	-	-	-
>45°	*	-	*	*	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
<30°	-	-	-	-	-	-	-	-
>45°	*	-	*	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
<30°	-	-	-	-	-	*	-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-
51 - 61 years								
<30°	-	-	-	-	-		-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-

> 60 years								
<30°	-	-	-	-	-		-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-
At least one use of spinal brace ever; n (%)								
No	187 (46.4%)	22 (34.4%)	105 (46.5%)	58 (57.4%)	-	*	-	*
Yes	43 (10.7%)	13 (20.3%)	24 (10.6%)	6 (5.9%)	-	-	-	-
Missing	173 (42.9%)	29 (45.3%)	97 (42.9%)	37 (36.6%)	*	*	*	6 (85.7%)
Surgery for scoliosis; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	15 (100.0%)	12 (100.0%)	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	25 (62.5%)	7 (58.3%)	15 (60.0%)	*	-	-	-	-
Yes	15 (37.5%)	5 (41.7%)	10 (40.0%)	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	79.7 (27.4)	*	76.2 (16.7)	*	-	-	-	-
Median [IQR]	81 [61.5, 101.5]	*	80.6 [64.5, 88]	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
11 - 16 years								
Mean (SD)	57.3 (31.1)	-	43 (19.4)	78.8 (32.9)	-	-	-	*
Median [IQR]	58.8 [33, 82]	-	40 [28.5, 58.9]	87 [63, 98]	-	-	-	*
Missing	*	-	*	*	-	-	-	-
16 - 21 years								
Mean (SD)	64.3 (28.8)	*	55 (21.1)	83 (27.2)	-	-	-	-
Median [IQR]	63 [44.5, 79]	*	52 [39, 69]	76 [63, 96]	-	-	-	-
Missing	*	-	*	-	-	-	-	-
21 - 31 years								
Mean (SD)	33.6 (25)	*	36.2 (25.4)	*	-	-	-	-
Median [IQR]	21.5 [12.2, 52.5]	*	22 [19, 60]	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
31 - 41 years								
Mean (SD)	39.4 (26.1)	*	41.7 (25.9)	-	-	-	-	-
Median [IQR]	34 [19, 45]	*	34.5 [21.2, 48.5]	-	-	-	-	-
Missing	*	-	*	-	-	-	-	-
41 - 51 years								
Mean (SD)	64.9 (33.6)	-	48 (24.9)	*	-	-	-	-
Median [IQR]	64 [36, 87.5]	-	42.2 [31.5, 61.2]	*	-	-	-	-
Missing	*	-	-	*	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	*	*	-	-	-	-

Median [IQR]	*	-	*	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Forced vital capacity volume								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-

Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	*	-	-	*	-	-	-	-
At least one episode of airway clearance assistance; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	*	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	6 (31.6%)	*	*	-	-	-	-	-
Yes	13 (68.4%)	10 (83.3%)	*	-	-	-	-	-
6 - 11 years								
No	9 (28.1%)	*	5 (23.8%)	*	-	-	-	-
Yes	23 (71.9%)	7 (77.8%)	16 (76.2%)	-	-	-	-	-
11 - 16 years								
No	17 (37.8%)	*	9 (28.1%)	7 (63.6%)	-	-	-	-

Yes	28 (62.2%)	*	23 (71.9%)	*	-	-	-	-
16 - 21 years								
No	20 (44.4%)	-	14 (38.9%)	6 (85.7%)	-	-	-	-
Yes	25 (55.6%)	*	22 (61.1%)	*	-	-	-	-
21 - 31 years								
No	17 (45.9%)	*	12 (48.0%)	*	-	-	-	-
Yes	20 (54.1%)	7 (70.0%)	13 (52.0%)	-	-	-	-	-
31 - 41 years								
No	12 (42.9%)	*	6 (28.6%)	5 (83.3%)	-	-	-	-
Yes	16 (57.1%)	-	15 (71.4%)	*	-	-	-	-
41 - 51 years								
No	16 (64.0%)	-	8 (50.0%)	8 (88.9%)	-	-	-	-
Yes	9 (36.0%)	-	8 (50.0%)	*	-	-	-	-
51 - 61 years								
No	12 (52.2%)	-	*	9 (69.2%)	*	-	-	-
Yes	11 (47.8%)	-	7 (77.8%)	*	-	-	-	-
> 60 years								
No	5 (71.4%)	-	-	5 (71.4%)	-	-	-	-
Yes	*	-	-	*	-	-	-	-
At least one episode of any non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-

Yes	*	*	-	-	-	-	-	*
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	5 (100.0%)	*	-	-	-	-	-	*
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	14 (100.0%)	12 (100.0%)	*	-	-	-	-	*
6 - 11 years								
No	*	-	*	-	-	-	-	-
Yes	14 (93.3%)	*	9 (90.0%)	*	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	35 (100.0%)	*	30 (100.0%)	*	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
Yes	28 (96.6%)	5 (100.0%)	23 (95.8%)	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
Yes	23 (95.8%)	9 (100.0%)	14 (93.3%)	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	9 (100.0%)	-	9 (100.0%)	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	9 (100.0%)	-	7 (100.0%)	*	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	10 (100.0%)	-	7 (100.0%)	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
At least one episode of full-time non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	12 (85.7%)	10 (83.3%)	*	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	13 (86.7%)	*	9 (90.0%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
11 - 16 years								
No	35 (100.0%)	*	30 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	29 (100.0%)	5 (100.0%)	24 (100.0%)	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	24 (100.0%)	9 (100.0%)	15 (100.0%)	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	8 (88.9%)	-	8 (88.9%)	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	8 (88.9%)	-	6 (85.7%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	10 (100.0%)	-	7 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	5 (100.0%)	*	-	-	-	-	-	*

Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	5 (100.0%)	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	11 (78.6%)	9 (75.0%)	*	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	12 (80.0%)	*	9 (90.0%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
11 - 16 years								
No	30 (85.7%)	*	26 (86.7%)	*	-	-	-	-
Yes	5 (14.3%)	*	*	-	-	-	-	-
16 - 21 years								
No	27 (93.1%)	*	24 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	18 (75.0%)	5 (55.6%)	13 (86.7%)	-	-	-	-	-
Yes	6 (25.0%)	*	*	-	-	-	-	-
31 - 41 years								
No	5 (55.6%)	-	5 (55.6%)	-	-	-	-	-

Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	7 (77.8%)	-	5 (71.4%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	*	-	*	-	-	-	-	-
Yes	8 (80.0%)	-	5 (71.4%)	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time non-invasive ventilation episode (years)								
Mean (SD)	7.4 (9.2)	*	*	-	-	-	-	-
Median [IQR]	2 [0.6, 11.6]	*	*	-	-	-	-	-
Missing	395 (98.0%)	60 (93.8%)	222 (98.2%)	101 (100.0%)	*	*	*	7 (100.0%)
At least one episode of any invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-

< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	*	-	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
11 - 16 years								
No	*	-	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-

31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
11 - 16 years								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								

No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time invasive ventilation episode (years)								
Mean (SD)	3.7 (5.1)	3.3 (5.4)	*	-	-	-	-	-
Median [IQR]	2.7 [0.5, 3.8]	1 [0.5, 3.4]	*	-	-	-	-	-
Missing	390 (96.8%)	53 (82.8%)	224 (99.1%)	101 (100.0%)	*	*	*	7 (100.0%)
Pulmonary infections reported in cause of hospitalisation or as a comorbidity; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	-	-	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-

< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	*	-	*	*	-	-	-	-
Yes	8 (80.0%)	*	*	-	-	-	-	-
11 - 16 years								
No	*	-	*	-	-	-	-	-
Yes	13 (86.7%)	*	10 (83.3%)	*	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	12 (100.0%)	*	10 (100.0%)	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	7 (100.0%)	*	*	-	-	-	-	-

31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
At least one episode of feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	11 (100.0%)	11 (100.0%)	-	-	-	-	-	-

6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	6 (100.0%)	*	*	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	11 (100.0%)	*	8 (100.0%)	-	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of exclusive feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	-	-	-	-	-	-	-	-
Yes	11 (100.0%)	11 (100.0%)	-	-	-	-	-	-
6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	6 (100.0%)	*	*	-	-	-	-	-
11 - 16 years								
No	5 (45.5%)	*	*	-	-	-	-	-
Yes	6 (54.5%)	*	*	-	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-

51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of supplementary feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	5 (100.0%)	5 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	11 (100.0%)	11 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	6 (100.0%)	*	*	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	6 (54.5%)	*	*	-	-	-	-	-
Yes	5 (45.5%)	*	*	-	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one case of gastrostomy; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	*	-

Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	22 (100.0%)	15 (100.0%)	6 (100.0%)	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	21 (100.0%)	6 (100.0%)	14 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	34 (100.0%)	5 (100.0%)	23 (100.0%)	6 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	24 (100.0%)	*	18 (100.0%)	5 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	13 (100.0%)	*	9 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	6 (100.0%)	*	*	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	9 (100.0%)	-	7 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	6 (100.0%)	-	*	*	-	-	-	-

Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at first gastrostomy (years)								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	403 (100.0%)	64 (100.0%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
At least one hospitalisation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	-	-	-	-	-	-	*
Yes	*	*	-	-	-	-	*	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	*
1.5 - 2 years								
No	*	*	-	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	5 (22.7%)	*	*	-	-	-	-	*
Yes	17 (77.3%)	11 (91.7%)	5 (62.5%)	-	-	-	-	*
6 - 11 years								
No	*	-	*	*	-	-	-	-
Yes	16 (80.0%)	*	11 (78.6%)	*	-	-	-	-
11 - 16 years								

J18 (Pneumonia, organism unspecified)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
R57.9 (Shock, unspecified)	-	-	-	-	-	-	-	-
R57.1 (Hypovolaemic shock)	*	*	-	-	-	-	-	-
R96.0 (Instantaneous death)	-	-	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle accident, traffic)	-	-	-	-	-	-	-	-
Missing	401 (99.5%)	62 (96.9%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Causes of death - Level 2; n (%)								
A49 (Bacterial infection of unspecified site)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
R57 (Shock, not elsewhere classified)	*	*	-	-	-	-	-	-
R96 (Other sudden death, cause unknown)	-	-	-	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
V89 (Motor- or nonmotor-vehicle accident, type of vehicle unspecified)	-	-	-	-	-	-	-	-
Missing	401 (99.5%)	62 (96.9%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Causes of death - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
J (Diseases of the respiratory system)	*	*	-	-	-	-	-	-

R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	*	*	-	-	-	-	-	-
U (Codes for special purposes)	-	-	-	-	-	-	-	-
V (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Missing	401 (99.5%)	62 (96.9%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Causes of hospitalisation - Level 1; n (%)								
A02.0 (Salmonella enteritis)	-	-	-	-	-	-	-	-
A04.7 (Enterocolitis due to Clostridium difficile)	-	-	-	-	-	-	-	-
A09.0 (Other and unspecified gastroenteritis and colitis of infectious origin)	-	-	-	-	-	-	-	-
A09.9 (Gastroenteritis and colitis of unspecified origin)	-	-	-	-	-	-	-	-
A46.9 (Erysipelas)	-	-	-	-	-	-	-	-
B34.2 (Coronavirus infection, unspecified site, excl. COVID-19)	-	-	-	-	-	-	-	-
B96.5 (Pseudomonas (aeruginosa) as the cause of diseases classified to other chapters)	*	-	-	*	-	-	-	-
B97.2 (Coronavirus as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80.9 (Malignant neoplasm, primary site unspecified)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	-	-	-	-	-	-	-	-
D50.9 (Iron deficiency anaemia, unspecified)	-	-	-	-	-	-	-	-
E08.1 (Diabetes mellitus due to underlying condition with ketoacidosis)	-	-	-	-	-	-	-	-

E10.1 (Diabetes mellitus with ketoacidosis)	-	-	-	-	-	-	-	-
E46 (Unspecified protein-calorie malnutrition)	-	-	-	-	-	-	-	-
E86.0 (Dehydration)	*	*	-	-	-	-	-	-
E87.2 (Acidosis)	*	-	*	-	-	-	-	-
E87.6 (Hypokalemia)	-	-	-	-	-	-	-	-
F31 (Bipolar disorder)	-	-	-	-	-	-	-	-
F98.9 (Unspecified behavioral and emotional disorders with onset usually occurring in childhood and	-	-	-	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40.8 (Other epilepsy)	*	-	-	*	-	-	-	-
G40.9 (Epilepsy, unspecified)	-	-	-	-	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45.9 (Transient cerebral ischaemic attack, unspecified)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	-	-	-	-	-	-	-	-
G83.0 (Diplegia of upper limbs)	-	-	-	-	-	-	-	-
G97.1 (Other reaction to spinal and lumbar puncture)	-	-	-	-	-	-	-	-
H60.9 (Otitis externa, unspecified)	-	-	-	-	-	-	-	-
H65.0 (Acute serous otitis media)	-	-	-	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21.9 (Acute myocardial infarction, unspecified)	-	-	-	-	-	-	-	-
I63.9 (Cerebral infarction, unspecified)	-	-	-	-	-	-	-	-
I70.2 (Atherosclerosis of arteries of extremities)	-	-	-	-	-	-	-	-
I86.3 (Vulval varices)	-	-	-	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-
J03.9 (Acute tonsillitis, unspecified)	-	-	-	-	-	-	-	-

J06.9 (Acute upper respiratory infection, unspecified)	*	-	*	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	-	-	-	-	-	-	-	-
J09.9 (Influenza due to identified novel influenza A virus with other manifestations)	-	-	-	-	-	-	-	-
J10.0 (Influenza with pneumonia, seasonal influenza virus identified)	-	-	-	-	-	-	-	-
J12.1 (Respiratory syncytial virus pneumonia)	-	-	-	-	-	-	-	-
J12.8 (Other viral pneumonia)	*	-	*	-	-	-	-	-
J12.9 (Viral pneumonia, unspecified)	-	-	-	-	-	-	-	-
J15.1 (Pneumonia due to Pseudomonas)	*	-	*	-	-	-	-	-
J15.2 (Pneumonia due to staphylococcus)	-	-	-	-	-	-	-	-
J15.6 (Pneumonia due to other Gram-negative bacteria)	-	-	-	-	-	-	-	-
J15.7 (Pneumonia due to Mycoplasma pneumoniae)	-	-	-	-	-	-	-	-
J15.8 (Other bacterial pneumonia)	-	-	-	-	-	-	-	-
J15.9 (Bacterial pneumonia, unspecified)	-	-	-	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	-	-	-	-	-	-	-	-
J16.8 (Pneumonia due to other specified infectious organisms)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J18.0 (Bronchopneumonia, unspecified)	-	-	-	-	-	-	-	-
J18.9 (Pneumonia, unspecified)	-	-	-	-	-	-	-	-

J20 (Acute bronchitis)	-	-	-	-	-	-	-	-
J20.9 (Acute bronchitis, unspecified)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	-	-	-	-	-	-	-	-
J21.0 (Acute bronchiolitis due to respiratory syncytial virus)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-
J35.1 (Hypertrophy of tonsils)	-	-	-	-	-	-	-	-
J35.3 (Hypertrophy of tonsils with hypertrophy of adenoids)	-	-	-	-	-	-	-	-
J69.0 (Pneumonitis due to food and vomit)	-	-	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
J96.9 (Respiratory failure, unspecified)	-	-	-	-	-	-	-	-
J98.1 (Pulmonary collapse)	-	-	-	-	-	-	-	-
J98.7 (Respiratory infections, not elsewhere classified)	5 (17.9%)	*	*	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	-	-	-	-	-	-	-	-
K57.3 (Diverticular disease of large intestine without perforation or abscess)	-	-	-	-	-	-	-	-
K59.0 (Constipation)	-	-	-	-	-	-	-	-
K63.1 (Perforation of intestine (nontraumatic))	-	-	-	-	-	-	-	-
K71.2 (Toxic liver disease with acute hepatitis)	-	-	-	-	-	-	-	-

K80.0 (Calculus of gallbladder with acute cholecystitis)	-	-	-	-	-	-	-	-
K80.1 (Calculus of gallbladder with other cholecystitis)	-	-	-	-	-	-	-	-
K81.0 (Acute cholecystitis)	-	-	-	-	-	-	-	-
K82.9 (Disease of gallbladder, unspecified)	*	-	*	-	-	-	-	-
K92.9 (Disease of digestive system, unspecified)	*	-	*	-	-	-	-	-
K94.2 (Gastrostomy complications)	-	-	-	-	-	-	-	-
M41 (Scoliosis)	*	-	*	-	-	-	-	-
M41.4 (Neuromuscular scoliosis)	-	-	-	-	-	-	-	-
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M80.0 (Postmenopausal osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M81 (Osteoporosis without pathological fracture)	-	-	-	-	-	-	-	-
M96.6 (Fracture of bone following insertion of orthopaedic implant, joint prosthesis, or bone plate)	-	-	-	-	-	-	-	-
N04 (Nephrotic syndrome)	-	-	-	-	-	-	-	-
N20.1 (Calculus of ureter)	-	-	-	-	-	-	-	-
N32.8 (Other specified disorders of bladder)	-	-	-	-	-	-	-	-
N41.2 (Abscess of prostate)	-	-	-	-	-	-	-	-
N83.2 (Other and unspecified ovarian cysts)	-	-	-	-	-	-	-	-
R00.2 (Palpitations)	*	-	*	-	-	-	-	-
R06 (Abnormalities of breathing)	*	*	-	-	-	-	-	-
R06.0 (Dyspnoea)	-	-	-	-	-	-	-	-
R09.2 (Respiratory arrest)	*	*	-	-	-	-	-	-

R11 (Nausea and vomiting)	-	-	-	-	-	-	-	-
R33 (Retention of urine)	-	-	-	-	-	-	-	-
R41.8 (Other and unspecified symptoms and signs involving cognitive functions and awareness)	-	-	-	-	-	-	-	-
R50.9 (Fever, unspecified)	-	-	-	-	-	-	-	-
R51 (Headache)	-	-	-	-	-	-	-	-
R56.0 (Febrile convulsions)	-	-	-	-	-	-	-	-
R63.3 (Feeding difficulties and mismanagement)	-	-	-	-	-	-	-	-
R63.6 (Insufficient intake of food and water)	*	-	*	-	-	-	-	-
R65.2 (Systemic Inflammatory Response Syndrome of non-infectious origin without organ failure)	-	-	-	-	-	-	-	-
R73.9 (Hyperglycaemia, unspecified)	-	-	-	-	-	-	-	-
S00.9 (Superficial injury of head, part unspecified)	-	-	-	-	-	-	-	-
S36.9 (Injury of unspecified intra-abdominal organ)	-	-	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S72.0 (Fracture of neck of femur)	-	-	-	-	-	-	-	-
S72.4 (Fracture of lower end of femur)	-	-	-	-	-	-	-	-
S73.0 (Dislocation of hip)	-	-	-	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	-	-	-	-	-	-	-	-
S82.9 (Fracture of lower leg, part unspecified)	-	-	-	-	-	-	-	-
T14.2 (Fracture of unspecified body region)	*	-	*	*	-	-	-	-
T45.0 (Antiallergic and antiemetic drugs)	-	-	-	-	-	-	-	-
T73.0 (Effects of hunger)	-	-	-	-	-	-	-	-

T81.0 (Haemorrhage and haematoma complicating a procedure, not elsewhere classified)	-	-	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	*	-	*	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	*	-	*	-	-	-	-	-
Y79.2 (Prosthetic and other implants, materials and accessory orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38.0 (Singleton, born in hospital)	-	-	-	-	-	-	-	-
Z47.8 (Other specified orthopaedic follow-up care)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 2; n (%)								
A02 (Other salmonella infections)	-	-	-	-	-	-	-	-
A04 (Other bacterial intestinal infections)	-	-	-	-	-	-	-	-
A09 (Other gastroenteritis and colitis of infectious and unspecified origin)	-	-	-	-	-	-	-	-
A46 (Erysipelas)	-	-	-	-	-	-	-	-
B34 (Viral infection of unspecified site)	-	-	-	-	-	-	-	-
B96 (Other specified bacterial agents as the cause of diseases classified to other chapters)	*	-	-	*	-	-	-	-
B97 (Viral agents as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80 (Malignant neoplasm, without specification of site)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	-	-	-	-	-	-	-	-

E08 (Diabetes mellitus due to underlying condition)	-	-	-	-	-	-	-	-
E10 (Type 1 diabetes mellitus)	-	-	-	-	-	-	-	-
E46 (Unspecified protein-energy malnutrition)	-	-	-	-	-	-	-	-
E86 (Volume depletion)	*	*	-	-	-	-	-	-
E87 (Other disorders of fluid, electrolyte and acid-base balance)	*	-	*	-	-	-	-	-
F31 (Bipolar affective disorder)	-	-	-	-	-	-	-	-
F98 (Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence)	-	-	-	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40 (Epilepsy)	*	-	-	*	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45 (Transient cerebral ischaemic attacks and related syndromes)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	-	-	-	-	-	-	-	-
G83 (Other paralytic syndromes)	-	-	-	-	-	-	-	-
G97 (Postprocedural disorders of nervous system, not elsewhere classified)	-	-	-	-	-	-	-	-
H60 (Otitis externa)	-	-	-	-	-	-	-	-
H65 (Nonsuppurative otitis media)	-	-	-	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21 (Acute myocardial infarction)	-	-	-	-	-	-	-	-
I63 (Cerebral infarction)	-	-	-	-	-	-	-	-
I70 (Atherosclerosis)	-	-	-	-	-	-	-	-
I86 (Varicose veins of other sites)	-	-	-	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-

J06 (Acute upper respiratory infections of multiple and unspecified sites)	*	-	*	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	-	-	-	-	-	-	-	-
J10 (Influenza due to identified seasonal influenza virus)	-	-	-	-	-	-	-	-
J12 (Viral pneumonia, not elsewhere classified)	*	-	*	-	-	-	-	-
J15 (Bacterial pneumonia, not elsewhere classified)	*	-	*	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J20 (Acute bronchitis)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	*	*	-	-	-	-	-	-
J35 (Chronic diseases of tonsils and adenoids)	-	-	-	-	-	-	-	-
J69 (Pneumonitis due to solids and liquids)	-	-	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J98 (Other respiratory disorders)	5 (17.9%)	*	*	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	-	-	-	-	-	-	-	-
K57 (Diverticular disease of intestine)	-	-	-	-	-	-	-	-
K59 (Other functional intestinal disorders)	-	-	-	-	-	-	-	-
K63 (Other diseases of intestine)	-	-	-	-	-	-	-	-

K71 (Toxic liver disease)	-	-	-	-	-	-	-	-
K80 (Cholelithiasis)	-	-	-	-	-	-	-	-
K81 (Cholecystitis)	-	-	-	-	-	-	-	-
K82 (Other diseases of gallbladder)	*	-	*	-	-	-	-	-
K92 (Other diseases of digestive system)	*	-	*	-	-	-	-	-
K94 (Complications of artificial openings of the digestive system)	-	-	-	-	-	-	-	-
M41 (Scoliosis)	*	-	*	-	-	-	-	-
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M81 (Osteoporosis without pathological fracture)	-	-	-	-	-	-	-	-
M96 (Postprocedural musculoskeletal disorders, not elsewhere classified)	-	-	-	-	-	-	-	-
N04 (Nephrotic syndrome)	-	-	-	-	-	-	-	-
N20 (Calculus of kidney and ureter)	-	-	-	-	-	-	-	-
N32 (Other disorders of bladder)	-	-	-	-	-	-	-	-
N41 (Inflammatory diseases of prostate)	-	-	-	-	-	-	-	-
N83 (Noninflammatory disorders of ovary, fallopian tube and broad ligament)	-	-	-	-	-	-	-	-
R00 (Abnormalities of heart beat)	*	-	*	-	-	-	-	-
R06 (Abnormalities of breathing)	*	*	-	-	-	-	-	-
R09 (Other symptoms and signs involving the circulatory and respiratory systems)	*	*	-	-	-	-	-	-
R11 (Nausea and vomiting)	-	-	-	-	-	-	-	-
R33 (Retention of urine)	-	-	-	-	-	-	-	-
R41 (Other symptoms and signs involving cognitive functions and awareness)	-	-	-	-	-	-	-	-

R50 (Fever of other and unknown origin)	-	-	-	-	-	-	-	-
R51 (Headache)	-	-	-	-	-	-	-	-
R56 (Convulsions, not elsewhere classified)	-	-	-	-	-	-	-	-
R63 (Symptoms and signs concerning food and fluid intake)	*	-	*	-	-	-	-	-
R65 (Systemic Inflammatory Response Syndrome [SIRS])	-	-	-	-	-	-	-	-
R73 (Elevated blood glucose level)	-	-	-	-	-	-	-	-
S00 (Superficial injury of head)	-	-	-	-	-	-	-	-
S36 (Injury of intra-abdominal organs)	-	-	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S73 (Dislocation, sprain and strain of joint and ligaments of hip)	-	-	-	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	-	-	-	-	-	-	-	-
S82 (Fracture of lower leg, including ankle)	-	-	-	-	-	-	-	-
T14 (Injury of unspecified body region)	*	-	*	*	-	-	-	-
T45 (Poisoning by primarily systemic and haematological agents, not elsewhere classified)	-	-	-	-	-	-	-	-
T73 (Effects of other deprivation)	-	-	-	-	-	-	-	-
T81 (Complications of procedures, not elsewhere classified)	-	-	-	-	-	-	-	-
U07 (Emergency use of U07)	*	-	*	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	*	-	*	-	-	-	-	-
Y79 (Orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-

Z38 (Liveborn infants according to place of birth and type of delivery)	-	-	-	-	-	-	-	-
Z47 (Other orthopaedic follow-up care)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
B (Certain infectious and parasitic diseases)	*	-	-	*	-	-	-	-
C (Neoplasms)	-	-	-	-	-	-	-	-
D (Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism)	-	-	-	-	-	-	-	-
E (Endocrine, nutritional and metabolic diseases)	*	*	*	-	-	-	-	-
F (Mental and behavioural disorders)	-	-	-	-	-	-	-	-
G (Diseases of the nervous system)	*	-	-	*	-	-	-	-
H (Diseases of the ear and mastoid process)	-	-	-	-	-	-	-	-
I (Diseases of the circulatory system)	-	-	-	-	-	-	-	-
J (Diseases of the respiratory system)	11 (39.3%)	*	7 (41.2%)	-	-	-	-	-
K (Diseases of the digestive system)	*	-	*	-	-	-	-	-
M (Diseases of the musculoskeletal system and connective tissue)	*	-	*	-	-	-	-	-
N (Diseases of the genitourinary system)	-	-	-	-	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	5 (17.9%)	*	*	-	-	-	-	-
S (Injury, poisoning and certain other consequences of external causes)	-	-	-	-	-	-	-	-
T (Injury, poisoning and certain other consequences of external causes)	*	-	*	*	-	-	-	-

U (Codes for special purposes)	*	-	*	-	-	-	-	-
W (External causes of morbidity and mortality)	*	-	*	-	-	-	-	-
Y (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Z (Factors influencing health status and contact with health services)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Incidence rate of each listed comorbidity (per patient-year)								
Diabetes	0	0	0	0	*	*	*	0
Fractures	0	0	0	0	*	*	*	0
Hepatotoxicity	0	0	0	0	*	*	*	0
Non-vertebral fractures	0	0	0	0	*	*	*	0
Osteoporosis	0	0	0	0	*	*	*	0
Pulmonary infections	0	0	0	0	*	*	*	0
Sleep apnea	0	0	0	0	*	*	*	0
Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Mean (SD)	58.5 (21.8)	*	56.6 (15.2)	-	-	-	-	-
Median [IQR]	57 [47.2, 74.8]	*	55.8 [47.2, 70.4]	-	-	-	-	-
Missing	381 (94.5%)	60 (93.8%)	208 (92.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Best score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	58.9 (19.1)	*	53.7 (15.4)	-	-	-	-	-
Median [IQR]	56 [47.7, 70.9]	*	54.5 [40.9, 67.3]	-	-	-	-	-
Missing	383 (95.0%)	61 (95.3%)	209 (92.5%)	101 (100.0%)	*	*	*	7 (100.0%)
Most recent score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	57.6 (22.8)	*	55.1 (16)	-	-	-	-	-

Spinraza SMA Type								
Indicator	Overall (N = 1003)	SMA Type 1 (N = 215)	SMA Type 2 (N = 363)	SMA Type 3 (N = 411)	SMA Type 4 (N = 8)	SMA Type Other (N = 1)	SMA Type Presymptomatic (N = 2)	SMA Type Missing (N = 3)
Sex; n (%)								
Female	472 (47.1%)	91 (42.3%)	180 (49.6%)	193 (47.0%)	5 (62.5%)	*	-	*
Male	531 (52.9%)	124 (57.7%)	183 (50.4%)	218 (53.0%)	*	-	*	*
Missing	-	-	-	-	-	-	-	-
Registry; n (%)								
BE	157 (15.7%)	23 (10.7%)	57 (15.7%)	70 (17.0%)	5 (62.5%)	-	-	*
CZ/SK	212 (21.1%)	58 (27.0%)	71 (19.6%)	80 (19.5%)	*	-	*	-
DE/AT	226 (22.5%)	41 (19.1%)	77 (21.2%)	106 (25.8%)	*	-	-	-
ES	223 (22.2%)	56 (26.0%)	97 (26.7%)	70 (17.0%)	-	-	-	-
GB/IE	78 (7.8%)	15 (7.0%)	20 (5.5%)	43 (10.5%)	-	-	-	-
SE	107 (10.7%)	22 (10.2%)	41 (11.3%)	42 (10.2%)	-	*	-	*
Missing	-	-	-	-	-	-	-	-
Age at symptom onset (years)								
Mean (SD)	2.7 (5)	0.3 (0.9)	0.9 (0.8)	5.2 (6.1)	25.4 (14.4)	-	-	*
Median [IQR]	1 [0.5, 2]	0.2 [0.1, 0.3]	0.8 [0.6, 1.1]	3 [1.5, 6]	17 [14.4, 38]	-	-	*
Missing	69 (6.9%)	12 (5.6%)	13 (3.6%)	38 (9.2%)	*	*	*	*
Reason for genetic testing; n (%)								
Family screening	20 (2.0%)	*	5 (1.4%)	11 (2.7%)	-	*	-	*
Newborn screening	8 (0.8%)	5 (2.3%)	-	-	-	-	*	*
No screening	534 (53.2%)	108 (50.2%)	199 (54.8%)	220 (53.5%)	6 (75.0%)	-	-	*
Prenatal screening	*	-	-	*	-	-	-	-
Missing	439 (43.8%)	100 (46.5%)	159 (43.8%)	178 (43.3%)	*	-	-	-
Method used for genetic testing; n (%)								
ddPCR	-	-	-	-	-	-	-	-
DNA Sequencing	-	-	-	-	-	-	-	-
HRM	-	-	-	-	-	-	-	-
MLPA	294 (29.3%)	54 (25.1%)	96 (26.4%)	133 (32.4%)	5 (62.5%)	*	*	*

qRT-PCR	14 (1.4%)	*	*	9 (2.2%)	*	-	-	-
RFLP	*	-	*	-	-	-	-	-
Missing	694 (69.2%)	159 (74.0%)	264 (72.7%)	269 (65.5%)	*	-	-	-
SMN1 variant; n (%)								
Compound heterozygous deletion exon 7	32 (3.2%)	5 (2.3%)	10 (2.8%)	15 (3.6%)	*	-	-	*
Compound heterozygous substitutions	*	-	*	*	-	-	-	-
Homozygous deletion exon 7	903 (90.0%)	193 (89.8%)	332 (91.5%)	366 (89.1%)	7 (87.5%)	*	*	*
Missing	66 (6.6%)	17 (7.9%)	20 (5.5%)	29 (7.1%)	-	-	-	-
Functional status at genetic report; n (%)								
Non-sitter	160 (16.0%)	19 (8.8%)	89 (24.5%)	51 (12.4%)	*	-	-	-
Sitter	46 (4.6%)	*	36 (9.9%)	8 (1.9%)	-	-	-	-
Walker	53 (5.3%)	-	*	49 (11.9%)	-	-	-	-
Missing	744 (74.2%)	194 (90.2%)	234 (64.5%)	303 (73.7%)	7 (87.5%)	*	*	*
Achieved motor milestone at genetic report; n (%)								
Climb stairs	*	-	-	*	-	-	-	-
Crawl	*	*	*	*	-	-	-	-
Hold head without support	132 (13.2%)	15 (7.0%)	68 (18.7%)	48 (11.7%)	*	-	-	-
Roll onto side	28 (2.8%)	*	21 (5.8%)	*	-	-	-	-
Sit without support	39 (3.9%)	*	32 (8.8%)	6 (1.5%)	-	-	-	-
Stand with assistance	*	-	*	-	-	-	-	-
Stand without assistance	*	-	*	*	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	30 (3.0%)	-	-	30 (7.3%)	-	-	-	-
Walk with assistance	*	-	-	*	-	-	-	-
Walk without assistance	20 (2.0%)	-	*	16 (3.9%)	-	-	-	-
Missing	744 (74.2%)	194 (90.2%)	234 (64.5%)	303 (73.7%)	7 (87.5%)	*	*	*
Best functional status; n (%)								

Non-sitter	10 (1.0%)	*	5 (1.4%)	*	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Missing	993 (99.0%)	211 (98.1%)	358 (98.6%)	410 (99.8%)	8 (100.0%)	*	*	*
Best achieved motor milestone; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	*	-	*	-	-	-	-	-
Roll onto side	6 (0.6%)	*	*	*	-	-	-	-
Sit without support	-	-	-	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	-	-	-
Missing	993 (99.0%)	211 (98.1%)	358 (98.6%)	410 (99.8%)	8 (100.0%)	*	*	*
Best functional status before treatment; n (%)								
Non-sitter	*	*	*	-	-	-	-	-
Sitter	10 (1.0%)	-	10 (2.8%)	-	-	-	-	-
Walker	16 (1.6%)	-	*	13 (3.2%)	*	-	-	-
Missing	975 (97.2%)	214 (99.5%)	350 (96.4%)	398 (96.8%)	7 (87.5%)	*	*	*
Best functional status after treatment; n (%)								
Non-sitter	73 (7.3%)	46 (21.4%)	19 (5.2%)	6 (1.5%)	-	-	*	-
Sitter	342 (34.1%)	90 (41.9%)	230 (63.4%)	22 (5.4%)	-	-	-	-
Walker	492 (49.1%)	28 (13.0%)	95 (26.2%)	358 (87.1%)	8 (100.0%)	*	-	*
Missing	96 (9.6%)	51 (23.7%)	19 (5.2%)	25 (6.1%)	-	-	-	*
Best achieved motor milestone before treatment; n (%)								
Climb stairs	8 (0.8%)	-	-	7 (1.7%)	*	-	-	-

1 - 3 months								
Mean (SD)	54.1 (4.5)	55.4 (3.1)	-	-	-	-	*	*
Median [IQR]	55 [52, 56]	56 [53.5, 56.5]	-	-	-	-	*	*
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	62 (3.2)	62 (3.2)	-	-	-	-	-	-
Median [IQR]	62 [61, 63.2]	62 [61, 63.2]	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	75.3 (4.5)	74.8 (5.2)	76.1 (2.3)	-	-	*	-	*
Median [IQR]	75 [73, 78]	75.6 [72.5, 77.2]	75 [75, 78]	-	-	*	-	*
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	81.9 (4.5)	81.4 (4.6)	81.9 (4.1)	*	-	-	-	-
Median [IQR]	81 [80, 85]	80.8 [78.2, 86]	81 [80, 82.2]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	102.4 (9.8)	102.4 (10.3)	100.9 (8.8)	106.7 (9.5)	-	-	-	-
Median [IQR]	104 [94, 110]	101.8 [94, 110]	102 [93, 107]	107.5 [100.5, 116]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	125.2 (17.7)	125.5 (11.8)	120 (20.6)	132.8 (11.8)	-	-	-	-
Median [IQR]	126 [118, 135]	126 [115, 135]	124 [113.4, 130]	133 [125.1, 140]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	153 (12.1)	151.8 (8.7)	146.9 (10)	158.4 (11.8)	-	-	-	-
Median [IQR]	152 [143.5, 162.8]	152 [145.8, 159.5]	147 [140, 154.5]	159.8 [150.2, 168.8]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	161.3 (12.6)	155 (11.9)	155.4 (11.2)	166.9 (11.1)	-	-	-	-
Median [IQR]	162.5 [150, 170]	157.5 [147.5, 163.8]	154 [146, 165]	168.5 [160, 174.2]	-	-	-	-

Mean (SD)	6.2 (1.1)	6.2 (1.1)	-	-	-	-	-	-
Median [IQR]	6 [5.4, 7]	6 [5.4, 7]	-	-	-	-	-	-
Missing	17 (44.7%)	17 (44.7%)	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	8.6 (1.3)	8.5 (1.4)	8.9 (0.9)	-	-	*	-	*
Median [IQR]	8.6 [8, 9.4]	8.6 [7.9, 9]	9 [8, 9.7]	-	-	*	-	*
Missing	66 (53.2%)	51 (55.4%)	13 (46.4%)	*	-	-	-	*
1.5 - 2 years								
Mean (SD)	192.5 (1303.3)	9.7 (1.3)	568.4 (2232.9)	*	-	-	-	-
Median [IQR]	10 [9, 11]	10 [8.9, 10.5]	10 [10, 11]	*	-	-	-	-
Missing	66 (55.9%)	44 (57.9%)	21 (55.3%)	-	-	-	-	*
2 - 6 years								
Mean (SD)	16.3 (8.2)	15.2 (3.9)	15.4 (3.8)	21.7 (18.2)	-	-	-	-
Median [IQR]	15 [13, 18]	15 [12.5, 17.5]	14.8 [13, 16.8]	17.3 [14.8, 19.9]	-	-	-	-
Missing	163 (50.5%)	61 (45.5%)	78 (55.3%)	23 (48.9%)	-	-	-	*
6 - 11 years								
Mean (SD)	27.4 (10.6)	22.3 (7.2)	25.4 (9.6)	33.8 (10.8)	-	-	-	-
Median [IQR]	25.4 [19, 34]	20 [18, 26]	23 [18, 32]	31.5 [26, 41]	-	-	-	-
Missing	97 (39.3%)	17 (37.0%)	56 (42.7%)	24 (34.3%)	-	-	-	-
11 - 16 years								
Mean (SD)	44.9 (17.6)	35.2 (11.6)	39.2 (13.9)	53.5 (18.7)	-	-	-	-
Median [IQR]	40 [33.6, 55.5]	34.4 [31.5, 37.8]	38 [30.2, 45]	47.1 [38.5, 64]	-	-	-	-
Missing	81 (47.1%)	5 (31.2%)	43 (51.2%)	33 (45.8%)	-	-	-	-
16 - 21 years								
Mean (SD)	51 (19.5)	36.8 (8.6)	44.4 (19.8)	59.1 (17)	-	-	-	-
Median [IQR]	48 [38.1, 63.2]	36.2 [31.2, 42.4]	43 [29.4, 54]	54 [44.6, 75]	-	-	-	-
Missing	60 (49.2%)	*	27 (51.9%)	29 (48.3%)	-	-	-	*
21 - 31 years								
Mean (SD)	63.6 (19.4)	-	52.1 (16.9)	69.1 (18)	-	-	-	-
Median [IQR]	63 [49, 76]	-	49.5 [36.9, 65.5]	70 [59, 81]	-	-	-	-
Missing	59 (54.6%)	*	14 (46.7%)	42 (56.0%)	*	-	-	*

31 - 41 years								
Mean (SD)	60.8 (20.1)	-	44.8 (13.2)	74.1 (14.3)	-	-	-	-
Median [IQR]	62 [45, 76.5]	-	45 [35.9, 53]	73.8 [65.2, 85]	-	-	-	-
Missing	48 (59.3%)	*	8 (34.8%)	37 (67.3%)	*	-	-	-
41 - 51 years								
Mean (SD)	79.8 (18.4)	-	62.6 (6.6)	82.5 (18.7)	*	-	-	-
Median [IQR]	75.5 [65.8, 92]	-	60 [60, 70]	80.5 [66.8, 95.2]	*	-	-	-
Missing	29 (37.7%)	-	6 (54.5%)	23 (36.5%)	-	-	-	-
51 - 61 years								
Mean (SD)	68.1 (22.1)	-	48 (14.7)	73.3 (20.7)	-	-	-	-
Median [IQR]	65.5 [55, 79]	-	53 [40, 55]	68 [61.5, 84]	-	-	-	-
Missing	21 (38.2%)	-	-	21 (43.8%)	-	-	-	-
> 60 years								
Mean (SD)	78.2 (22.9)	-	-	79.1 (23.6)	*	-	-	-
Median [IQR]	72 [62, 90]	-	-	76.5 [61.8, 93.8]	*	-	-	-
Missing	10 (43.5%)	-	-	9 (42.9%)	*	-	-	-
Age at first acquisition of the best motor ability								
Mean (SD)	17.5 (17.4)	3.4 (4.3)	11.3 (10.4)	27.7 (18.7)	45.4 (11.9)	*	-	*
Median [IQR]	10.9 [3.7, 26]	2.3 [1.3, 3.8]	7.9 [3.8, 15.1]	23.2 [11.4, 43.2]	44.3 [37.4, 51.8]	*	-	*
Missing	264 (26.3%)	81 (37.7%)	98 (27.0%)	82 (20.0%)	-	-	*	*
Age at first loss of the best motor ability episodes								
Mean (SD)	26.3 (19.1)	8.8 (8.6)	17.2 (12.4)	37.2 (19.2)	*	-	-	-
Median [IQR]	19.4 [11, 41.6]	6.8 [3, 11.1]	15.4 [8, 21.1]	39.6 [20.1, 53.3]	*	-	-	-
Missing	748 (74.6%)	202 (94.0%)	240 (66.1%)	294 (71.5%)	6 (75.0%)	*	*	*
Full-time or part-time wheelchair use; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	5 (100.0%)	5 (100.0%)	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	16 (100.0%)	15 (100.0%)	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	47 (90.4%)	37 (92.5%)	10 (83.3%)	-	-	-	-	-
Yes	5 (9.6%)	*	*	-	-	-	-	-
1.5 - 2 years								
No	45 (63.4%)	29 (60.4%)	16 (69.6%)	-	-	-	-	-
Yes	26 (36.6%)	19 (39.6%)	7 (30.4%)	-	-	-	-	-
2 - 6 years								
No	7 (4.0%)	*	*	*	-	-	-	-
Yes	169 (96.0%)	70 (98.6%)	89 (95.7%)	10 (83.3%)	-	-	-	-
6 - 11 years								
No	15 (9.1%)	*	8 (8.2%)	*	-	-	-	-
Yes	149 (90.9%)	34 (89.5%)	89 (91.8%)	26 (89.7%)	-	-	-	-
11 - 16 years								
No	*	-	*	*	-	-	-	-
Yes	100 (97.1%)	9 (100.0%)	55 (96.5%)	36 (97.3%)	-	-	-	-
16 - 21 years								
No	*	-	*	*	-	-	-	-
Yes	81 (96.4%)	7 (100.0%)	34 (94.4%)	39 (97.5%)	-	-	-	*
21 - 31 years								
No	*	-	*	*	-	-	-	-
Yes	59 (96.7%)	-	24 (96.0%)	34 (97.1%)	-	-	-	*
31 - 41 years								
No	*	-	-	*	-	-	-	-
Yes	37 (97.4%)	*	16 (100.0%)	20 (95.2%)	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	38 (100.0%)	-	10 (100.0%)	27 (100.0%)	*	-	-	-

>1	10 (8.5%)	7 (9.2%)	*	-	-	-	-	-
0	101 (85.6%)	64 (84.2%)	33 (86.8%)	*	-	-	-	*
1	7 (5.9%)	5 (6.6%)	*	-	-	-	-	-
2 - 6 years								
>1	59 (18.3%)	37 (27.6%)	20 (14.2%)	*	-	-	-	-
0	238 (73.7%)	87 (64.9%)	110 (78.0%)	40 (85.1%)	-	-	-	*
1	26 (8.0%)	10 (7.5%)	11 (7.8%)	5 (10.6%)	-	-	-	-
6 - 11 years								
>1	75 (30.4%)	17 (37.0%)	45 (34.4%)	13 (18.6%)	-	-	-	-
0	143 (57.9%)	26 (56.5%)	69 (52.7%)	48 (68.6%)	-	-	-	-
1	29 (11.7%)	*	17 (13.0%)	9 (12.9%)	-	-	-	-
11 - 16 years								
>1	60 (34.9%)	5 (31.2%)	36 (42.9%)	19 (26.4%)	-	-	-	-
0	95 (55.2%)	11 (68.8%)	43 (51.2%)	41 (56.9%)	-	-	-	-
1	17 (9.9%)	-	5 (6.0%)	12 (16.7%)	-	-	-	-
16 - 21 years								
>1	42 (34.4%)	*	23 (44.2%)	16 (26.7%)	-	-	-	-
0	74 (60.7%)	6 (66.7%)	26 (50.0%)	41 (68.3%)	-	-	-	*
1	6 (4.9%)	-	*	*	-	-	-	-
21 - 31 years								
>1	21 (19.4%)	-	15 (50.0%)	6 (8.0%)	-	-	-	-
0	77 (71.3%)	*	14 (46.7%)	60 (80.0%)	*	-	-	*
1	10 (9.3%)	-	*	9 (12.0%)	-	-	-	-
31 - 41 years								
>1	19 (23.5%)	-	12 (52.2%)	7 (12.7%)	-	-	-	-
0	58 (71.6%)	*	11 (47.8%)	44 (80.0%)	*	-	-	-
1	*	-	-	*	-	-	-	-
41 - 51 years								
>1	8 (10.4%)	-	*	6 (9.5%)	-	-	-	-
0	64 (83.1%)	-	9 (81.8%)	52 (82.5%)	*	-	-	-
1	5 (6.5%)	-	-	5 (7.9%)	-	-	-	-

Mean (SD)	47 (11.7)	*	*	-	-	-	-	*
Median [IQR]	46.5 [46, 52.2]	*	*	-	-	-	-	*
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	53 (8.6)	48.4 (9.3)	57 (5.3)	-	-	-	-	-
Median [IQR]	53 [50.5, 60]	52 [40.5, 55.5]	57 [52.5, 61]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	51.1 (10.5)	50.1 (8)	50.8 (12.3)	58.8 (7.8)	-	-	-	-
Median [IQR]	54 [44, 58.5]	51.5 [41.8, 56]	54 [44.8, 60.8]	64 [58, 64]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	40.7 (11.8)	*	43.2 (11.6)	-	-	-	-	-
Median [IQR]	38 [31, 49]	*	41 [38, 54]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	29.7 (14.6)	*	26 (10.7)	*	-	-	-	-
Median [IQR]	30 [25.5, 31.5]	*	30 [24, 31]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	27.8 (7.3)	*	26.8 (8)	*	-	-	-	-
Median [IQR]	26 [23.8, 34]	*	25 [23, 33]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	17.7 (11)	-	*	*	-	-	-	*
Median [IQR]	20 [9, 27]	-	*	*	-	-	-	*
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-

< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	53.6 (22.8)	*	43.5 (16.1)	79.2 (11.4)	-	-	-	-
Median [IQR]	51 [41.2, 71.2]	*	46 [35.8, 51.5]	83 [81, 86]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	55.7 (30.6)	-	30.2 (12.4)	71.6 (27.6)	-	-	-	-
Median [IQR]	44 [36, 91]	-	36 [19, 42]	90.5 [44.8, 92.2]	-	-	-	-

Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	43.9 (24.3)	-	27 (9.1)	63.7 (21.5)	-	-	-	-
Median [IQR]	36 [32, 53]	-	32 [22, 34]	63.5 [42.5, 84.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	55 (26.7)	-	*	*	-	-	-	-
Median [IQR]	46 [30, 83]	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for 6MWT								
Mean (SD)	321.5 (152.8)	-	*	320.1 (151.1)	343.6 (192.8)	-	-	-
Median [IQR]	336 [202.5, 425]	-	*	330 [210, 418]	450 [120, 518]	-	-	-
Missing	896 (89.3%)	215 (100.0%)	362 (99.7%)	310 (75.4%)	*	*	*	*
Best score for 6MWT								
Mean (SD)	367.4 (153.4)	-	*	365.3 (153.1)	*	-	-	-

Median [IQR]	382 [270.5, 460.2]	-	*	376 [269, 458]	*	-	-	-
Missing	901 (89.8%)	215 (100.0%)	362 (99.7%)	314 (76.4%)	*	*	*	*
Most recent score for 6MWT								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	348.6 (158.4)	-	-	348.6 (158.4)	-	-	-	-
Median [IQR]	375 [300, 427.5]	-	-	375 [300, 427.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-

Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	*	-	-	-	-
Median [IQR]	-	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-

Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	*	-	-	-	-
Median [IQR]	-	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-

Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-

Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Age at report of (first) best CHOP-INTEND score								
Mean (SD)	6.5 (7.9)	3.6 (3.3)	7.9 (7.1)	19.2 (15.9)	-	-	*	*
Median [IQR]	3.3 [1.9, 7.3]	2.6 [1.7, 4.6]	4.8 [2.3, 12.6]	17.2 [3, 27.7]	-	-	*	*
Missing	807 (80.5%)	119 (55.3%)	282 (77.7%)	397 (96.6%)	8 (100.0%)	*	-	-
Age at report of (first) best HFMS(-E) score								
Mean (SD)	15.6 (14.1)	4.2 (2.4)	10.8 (9.2)	21.8 (15.4)	*	-	-	*
Median [IQR]	10.2 [5.4, 20.8]	3.8 [2.5, 5.2]	7.8 [5.1, 13.4]	17.4 [9.9, 28.9]	*	-	-	*
Missing	630 (62.8%)	168 (78.1%)	223 (61.4%)	231 (56.2%)	*	*	*	*
Age at report of (first) best RULM right side score								
Mean (SD)	10.5 (5.6)	5.6 (3.7)	10.7 (6.1)	12 (4.3)	-	-	-	*
Median [IQR]	9.7 [5.6, 14.6]	4.1 [3.3, 6.2]	9.5 [5.2, 16.8]	12.5 [8.8, 14.6]	-	-	-	*
Missing	910 (90.7%)	198 (92.1%)	326 (89.8%)	373 (90.8%)	8 (100.0%)	*	*	*

Age at report of (first) best HINE-2 score								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	1002 (99.9%)	214 (99.5%)	363 (100.0%)	411 (100.0%)	8 (100.0%)	*	*	*
Age at report of (first) best MFM32 score								
Mean (SD)	17.8 (13.6)	*	14 (8.9)	22 (15.9)	-	-	-	-
Median [IQR]	13.1 [7.6, 18.7]	*	12 [7, 17]	17.4 [11, 25.8]	-	-	-	-
Missing	946 (94.3%)	213 (99.1%)	337 (92.8%)	382 (92.9%)	8 (100.0%)	*	*	*
Age at report of (first) 6MWT best score								
Mean (SD)	22.7 (15.1)	-	*	21.9 (15)	39 (6.6)	-	-	-
Median [IQR]	17.9 [10.4, 30.6]	-	*	17.6 [10.4, 29.1]	39.1 [38.8, 43.6]	-	-	-
Missing	893 (89.0%)	215 (100.0%)	362 (99.7%)	307 (74.7%)	*	*	*	*
Ever diagnosed with scoliosis; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	10 (45.5%)	8 (44.4%)	-	-	-	-	*	*
Yes	12 (54.5%)	10 (55.6%)	*	-	-	-	-	-
1.5 - 2 years								
No	8 (50.0%)	5 (50.0%)	*	*	-	-	-	-
Yes	8 (50.0%)	5 (50.0%)	*	-	-	-	-	-

<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
<30°	*	*	*	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
<30°	*	*	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
<30°	20 (60.6%)	9 (47.4%)	10 (76.9%)	*	-	-	-	-
>45°	*	*	*	-	-	-	-	-
30-45°	9 (27.3%)	7 (36.8%)	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
<30°	21 (42.0%)	5 (41.7%)	12 (37.5%)	*	-	-	-	-

Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	78.9 (26.1)	63 (26.2)	85.9 (23.9)	*	-	-	-	-
Median [IQR]	81 [66, 97]	62.5 [43.6, 82.8]	85 [69.5, 102]	*	-	-	-	-
Missing	*	*	*	-	-	-	-	-
6 - 11 years								
Mean (SD)	73 (30.1)	31.7 (11.4)	67 (23.3)	99.3 (16.1)	-	-	-	-
Median [IQR]	76 [44, 96]	30.5 [23, 37.8]	67.8 [43.8, 88]	103 [85.6, 112]	-	-	-	-
Missing	6 (8.5%)	*	*	*	-	-	-	-
11 - 16 years								
Mean (SD)	71.8 (30.3)	*	53.2 (26.2)	89.9 (20.4)	-	-	-	-
Median [IQR]	79 [49.2, 94]	*	51.5 [38, 65]	91 [82, 104.1]	-	-	-	-
Missing	5 (6.7%)	*	*	-	-	-	-	-
16 - 21 years								
Mean (SD)	64 (32.3)	*	41.1 (23.4)	85.7 (22.9)	-	-	-	-
Median [IQR]	59.5 [32.5, 93.2]	*	32 [26.5, 57.5]	93 [73, 97.8]	-	-	-	-
Missing	7 (11.9%)	-	*	*	-	-	-	-
21 - 31 years								
Mean (SD)	75.4 (28.7)	-	45.4 (19.8)	88 (20.6)	*	-	-	*
Median [IQR]	87 [55, 98]	-	40 [32, 56.5]	91 [77.5, 101]	*	-	-	*
Missing	5 (10.0%)	-	*	*	-	-	-	-
31 - 41 years								
Mean (SD)	78 (37.9)	-	45.7 (47.2)	91.7 (20.9)	*	-	-	-
Median [IQR]	85.5 [57.5, 97.8]	-	22 [19.5, 60.5]	92 [83, 105]	*	-	-	-
Missing	5 (12.2%)	*	*	*	-	-	-	-
41 - 51 years								
Mean (SD)	91.5 (20.9)	-	*	94.5 (18.9)	*	-	-	-
Median [IQR]	91 [85, 105]	-	*	91.5 [86, 105.2]	*	-	-	-
Missing	*	-	-	*	-	-	-	-

51 - 61 years								
Mean (SD)	82.9 (35.8)	-	*	96.2 (24.7)	-	-	-	-
Median [IQR]	89 [66, 106]	-	*	94 [73, 108]	-	-	-	-
Missing	*	-	-	*	-	-	-	-
> 60 years								
Mean (SD)	90.2 (30.9)	-	-	90.1 (32.4)	*	-	-	-
Median [IQR]	93 [81, 104]	-	-	93.5 [77, 107]	*	-	-	-
Missing	*	-	-	-	*	-	-	-
Forced vital capacity volume								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	*	*	-	-	-	-	-	-

1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	0.8 (0.3)	*	0.9 (0.3)	-	-	-	-	-
Median [IQR]	0.8 [0.4, 1]	*	0.9 [0.8, 1.1]	-	-	-	-	-
Missing	17 (60.7%)	5 (55.6%)	10 (58.8%)	*	-	-	-	-
6 - 11 years								
Mean (SD)	1.3 (0.7)	0.5 (0.2)	0.9 (0.4)	1.9 (0.4)	-	-	-	-
Median [IQR]	1.5 [0.8, 1.9]	0.4 [0.4, 0.5]	0.9 [0.7, 1.1]	1.9 [1.6, 2.1]	-	-	-	-
Missing	27 (38.0%)	5 (45.5%)	18 (52.9%)	*	-	-	-	-
11 - 16 years								
Mean (SD)	2.1 (1.3)	*	1.2 (0.7)	3 (1)	-	-	-	-
Median [IQR]	2.2 [0.9, 2.8]	*	1 [0.5, 1.6]	2.7 [2.2, 3.5]	-	-	-	-
Missing	22 (29.3%)	-	14 (40.0%)	8 (21.6%)	-	-	-	-
16 - 21 years								
Mean (SD)	2.3 (1.5)	*	1.4 (0.9)	3.2 (1.2)	-	-	-	-
Median [IQR]	2 [1, 3.5]	*	1 [0.8, 1.6]	3.4 [2.2, 4.1]	-	-	-	-
Missing	18 (30.5%)	-	10 (37.0%)	8 (26.7%)	-	-	-	-
21 - 31 years								
Mean (SD)	3.3 (1.5)	-	1.7 (0.6)	3.9 (1.1)	*	-	-	*
Median [IQR]	3.4 [2, 4.3]	-	1.5 [1.3, 1.9]	3.9 [3.4, 5]	*	-	-	*
Missing	12 (24.0%)	-	*	8 (23.5%)	-	-	-	-
31 - 41 years								
Mean (SD)	3 (1.6)	-	0.9 (0.6)	3.9 (1)	*	-	-	-
Median [IQR]	3.6 [1.4, 4.2]	-	0.7 [0.6, 0.9]	4.1 [3.6, 4.7]	*	-	-	-
Missing	14 (34.1%)	*	6 (42.9%)	7 (29.2%)	-	-	-	-
41 - 51 years								
Mean (SD)	4.2 (1.3)	-	*	4.3 (1.2)	*	-	-	-
Median [IQR]	4.2 [3.3, 5.3]	-	*	4.6 [3.4, 5.2]	*	-	-	-

Missing	14 (41.2%)	-	*	12 (41.4%)	-	-	-	-
51 - 61 years								
Mean (SD)	3.1 (1.5)	-	*	3.6 (1.1)	-	-	-	-
Median [IQR]	3.2 [1.9, 4]	-	*	3.8 [2.9, 4.4]	-	-	-	-
Missing	10 (40.0%)	-	*	9 (42.9%)	-	-	-	-
> 60 years								
Mean (SD)	3.2 (1)	-	-	3.2 (1)	*	-	-	-
Median [IQR]	3.2 [3, 3.8]	-	-	3.3 [2.9, 3.9]	*	-	-	-
Missing	*	-	-	*	*	-	-	-
At least one episode of airway clearance assistance; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (100.0%)	5 (100.0%)	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	8 (80.0%)	8 (80.0%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	25 (78.1%)	16 (69.6%)	8 (100.0%)	*	-	-	-	-
Yes	7 (21.9%)	7 (30.4%)	-	-	-	-	-	-
1.5 - 2 years								
No	22 (71.0%)	7 (43.8%)	12 (100.0%)	*	-	-	-	-
Yes	9 (29.0%)	9 (56.2%)	-	-	-	-	-	-
2 - 6 years								
No	76 (47.8%)	16 (21.1%)	42 (66.7%)	18 (90.0%)	-	-	-	-
Yes	83 (52.2%)	60 (78.9%)	21 (33.3%)	*	-	-	-	-
6 - 11 years								
No	68 (45.9%)	*	35 (38.9%)	29 (90.6%)	-	-	-	-
Yes	80 (54.1%)	22 (84.6%)	55 (61.1%)	*	-	-	-	-

11 - 16 years								
No	58 (60.4%)	*	22 (41.5%)	33 (94.3%)	-	-	-	-
Yes	38 (39.6%)	5 (62.5%)	31 (58.5%)	*	-	-	-	-
16 - 21 years								
No	39 (61.9%)	*	12 (38.7%)	26 (89.7%)	-	-	-	-
Yes	24 (38.1%)	*	19 (61.3%)	*	-	-	-	-
21 - 31 years								
No	48 (71.6%)	-	7 (31.8%)	41 (93.2%)	-	-	-	-
Yes	19 (28.4%)	*	15 (68.2%)	*	-	-	-	-
31 - 41 years								
No	33 (78.6%)	*	5 (38.5%)	27 (96.4%)	-	-	-	-
Yes	9 (21.4%)	-	8 (61.5%)	*	-	-	-	-
41 - 51 years								
No	55 (94.8%)	-	5 (71.4%)	48 (98.0%)	*	-	-	-
Yes	*	-	*	*	-	-	-	-
51 - 61 years								
No	31 (81.6%)	-	*	29 (90.6%)	-	-	-	-
Yes	7 (18.4%)	-	*	*	-	-	-	-
> 60 years								
No	17 (100.0%)	-	-	16 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of any non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (37.5%)	6 (37.5%)	-	-	-	-	-	-
Yes	10 (62.5%)	10 (62.5%)	-	-	-	-	-	-
3 - 6 months								
No	16 (34.0%)	16 (34.0%)	-	-	-	-	-	-
Yes	31 (66.0%)	31 (66.0%)	-	-	-	-	-	-

6 - 18 months								
No	6 (9.0%)	5 (7.6%)	*	-	-	-	-	-
Yes	61 (91.0%)	61 (92.4%)	-	-	-	-	-	-
1.5 - 2 years								
No	7 (10.8%)	5 (7.9%)	*	-	-	-	-	-
Yes	58 (89.2%)	58 (92.1%)	-	-	-	-	-	-
2 - 6 years								
No	*	*	*	-	-	-	-	-
Yes	88 (96.7%)	71 (98.6%)	17 (89.5%)	-	-	-	-	-
6 - 11 years								
No	*	*	-	*	-	-	-	-
Yes	63 (96.9%)	26 (96.3%)	37 (100.0%)	-	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
Yes	49 (98.0%)	8 (88.9%)	40 (100.0%)	*	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
Yes	27 (96.4%)	5 (100.0%)	22 (95.7%)	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	8 (100.0%)	-	*	5 (100.0%)	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	7 (87.5%)	-	*	6 (85.7%)	-	-	-	-

> 60 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
At least one episode of full-time non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	16 (100.0%)	16 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	46 (97.9%)	46 (97.9%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	63 (94.0%)	62 (93.9%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	61 (93.8%)	59 (93.7%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	87 (95.6%)	68 (94.4%)	19 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	63 (96.9%)	25 (92.6%)	37 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
11 - 16 years								
No	49 (98.0%)	8 (88.9%)	40 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
16 - 21 years								
No	26 (92.9%)	*	23 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-

21 - 31 years								
No	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	8 (100.0%)	-	*	5 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	8 (100.0%)	-	*	7 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping non-invasive ventilation; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	16 (100.0%)	16 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	47 (100.0%)	47 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	66 (98.5%)	65 (98.5%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-

No	5 (29.4%)	5 (29.4%)	-	-	-	-	-	-
Yes	12 (70.6%)	12 (70.6%)	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-
Yes	31 (96.9%)	31 (96.9%)	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	17 (94.4%)	16 (94.1%)	*	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	8 (100.0%)	7 (100.0%)	*	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	5 (100.0%)	*	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

At least one episode of full-time invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	7 (100.0%)	7 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	11 (73.3%)	11 (73.3%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	13 (76.5%)	13 (76.5%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	20 (62.5%)	20 (62.5%)	-	-	-	-	-	-
Yes	12 (37.5%)	12 (37.5%)	-	-	-	-	-	-
6 - 11 years								
No	8 (44.4%)	7 (41.2%)	*	-	-	-	-	-
Yes	10 (55.6%)	10 (58.8%)	-	-	-	-	-	-
11 - 16 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-

Yes	*	*	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	7 (100.0%)	7 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	15 (100.0%)	15 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	17 (100.0%)	17 (100.0%)	-	-	-	-	-	-

< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	7 (100.0%)	7 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	15 (100.0%)	15 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	17 (100.0%)	17 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	30 (93.8%)	30 (93.8%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	17 (94.4%)	16 (94.1%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
11 - 16 years								
No	8 (100.0%)	7 (100.0%)	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	5 (100.0%)	*	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	*	*	*	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time invasive ventilation episode (years)								
Mean (SD)	1.2 (1)	1.2 (1)	*	-	-	-	-	-
Median [IQR]	0.9 [0.5, 1.2]	0.8 [0.5, 1.2]	*	-	-	-	-	-
Missing	981 (97.8%)	194 (90.2%)	362 (99.7%)	411 (100.0%)	8 (100.0%)	*	*	*
Pulmonary infections reported in cause of hospitalisation or as a comorbidity; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	5 (100.0%)	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	13 (100.0%)	12 (100.0%)	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	46 (95.8%)	36 (94.7%)	9 (100.0%)	*	-	-	-	-

Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	33 (94.3%)	19 (90.5%)	13 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	129 (95.6%)	64 (97.0%)	48 (92.3%)	17 (100.0%)	-	-	-	-
Yes	6 (4.4%)	*	*	-	-	-	-	-
6 - 11 years								
No	109 (96.5%)	24 (96.0%)	59 (98.3%)	26 (92.9%)	-	-	-	-
Yes	*	*	*	*	-	-	-	-
11 - 16 years								
No	73 (97.3%)	*	37 (97.4%)	32 (97.0%)	-	-	-	-
Yes	*	-	*	*	-	-	-	-
16 - 21 years								
No	54 (100.0%)	5 (100.0%)	23 (100.0%)	26 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	38 (100.0%)	-	15 (100.0%)	23 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	31 (100.0%)	-	14 (100.0%)	17 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	34 (100.0%)	-	6 (100.0%)	28 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	29 (100.0%)	-	5 (100.0%)	24 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	9 (100.0%)	-	-	7 (100.0%)	*	-	-	-

No	-	-	-	-	-	-	-	-
Yes	11 (100.0%)	*	9 (100.0%)	*	-	-	-	-
31 - 41 years								
No	*	-	-	*	-	-	-	-
Yes	5 (83.3%)	-	*	*	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	8 (100.0%)	-	*	*	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	7 (87.5%)	-	*	*	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	*	-	-	*	-	-	-	-
At least one episode of feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	8 (61.5%)	8 (61.5%)	-	-	-	-	-	-
Yes	5 (38.5%)	5 (38.5%)	-	-	-	-	-	-
3 - 6 months								
No	24 (60.0%)	24 (60.0%)	-	-	-	-	-	-
Yes	16 (40.0%)	16 (40.0%)	-	-	-	-	-	-
6 - 18 months								
No	19 (36.5%)	18 (35.3%)	*	-	-	-	-	-
Yes	33 (63.5%)	33 (64.7%)	-	-	-	-	-	-
1.5 - 2 years								
No	16 (30.2%)	16 (30.8%)	-	-	-	-	-	-
Yes	37 (69.8%)	36 (69.2%)	*	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	10 (76.9%)	10 (76.9%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	28 (70.0%)	28 (70.0%)	-	-	-	-	-	-
Yes	12 (30.0%)	12 (30.0%)	-	-	-	-	-	-
6 - 18 months								
No	23 (44.2%)	22 (43.1%)	*	-	-	-	-	-
Yes	29 (55.8%)	29 (56.9%)	-	-	-	-	-	-
1.5 - 2 years								
No	21 (39.6%)	20 (38.5%)	*	-	-	-	-	-
Yes	32 (60.4%)	32 (61.5%)	-	-	-	-	-	-
2 - 6 years								
No	19 (34.5%)	17 (34.0%)	*	-	-	-	-	-
Yes	36 (65.5%)	33 (66.0%)	*	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	16 (80.0%)	12 (75.0%)	*	-	-	-	-	-
11 - 16 years								
No	*	*	*	-	-	-	-	-
Yes	6 (60.0%)	*	*	*	-	-	-	-
16 - 21 years								
No	*	*	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-

41 - 51 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	*	-	*	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of supplementary feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	11 (84.6%)	11 (84.6%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	36 (90.0%)	36 (90.0%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	48 (92.3%)	47 (92.2%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	48 (90.6%)	48 (92.3%)	-	-	-	-	-	-
Yes	5 (9.4%)	*	*	-	-	-	-	-
2 - 6 years								
No	42 (76.4%)	39 (78.0%)	*	-	-	-	-	-

Yes	13 (23.6%)	11 (22.0%)	*	-	-	-	-	-
6 - 11 years								
No	19 (95.0%)	15 (93.8%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
11 - 16 years								
No	8 (80.0%)	*	*	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
16 - 21 years								
No	*	*	-	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	*	-	-	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one case of gastrostomy; n (%)								
< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

41 - 51 years								
No	34 (100.0%)	-	6 (100.0%)	28 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	29 (100.0%)	-	5 (100.0%)	24 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	9 (100.0%)	-	-	7 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at first gastrostomy (years)								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	1003 (100.0%)	215 (100.0%)	363 (100.0%)	411 (100.0%)	8 (100.0%)	*	*	*
At least one hospitalisation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1 - 3 months								
No	9 (64.3%)	9 (69.2%)	-	-	-	-	-	-
Yes	5 (35.7%)	*	-	-	-	-	*	-
3 - 6 months								
No	26 (72.2%)	26 (74.3%)	-	-	-	-	-	-
Yes	10 (27.8%)	9 (25.7%)	-	*	-	-	-	-
6 - 18 months								
No	34 (45.3%)	26 (44.8%)	7 (46.7%)	*	-	-	-	-
Yes	41 (54.7%)	32 (55.2%)	8 (53.3%)	*	-	-	-	-
1.5 - 2 years								
No	56 (65.1%)	40 (69.0%)	13 (54.2%)	*	-	-	-	-
Yes	30 (34.9%)	18 (31.0%)	11 (45.8%)	*	-	-	-	-
2 - 6 years								
No	44 (27.8%)	16 (21.3%)	21 (32.8%)	7 (36.8%)	-	-	-	-

Mean (SD)	38.1 (86)	15.5 (15.6)	*	-	-	-	-	-
Median [IQR]	11 [6, 24.2]	10 [6, 18]	*	-	-	-	-	-
Missing	967 (96.4%)	183 (85.1%)	359 (98.9%)	411 (100.0%)	8 (100.0%)	*	*	*
Causes of death - Level 1; n (%)								
A49.9 (Bacterial infection, unspecified)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
R57.9 (Shock, unspecified)	-	-	-	-	-	-	-	-
R57.1 (Hypovolaemic shock)	*	*	-	-	-	-	-	-
R96.0 (Instantaneous death)	*	-	*	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle accident, traffic)	-	-	-	-	-	-	-	-
Missing	1001 (99.8%)	214 (99.5%)	362 (99.7%)	411 (100.0%)	8 (100.0%)	*	*	*
Causes of death - Level 2; n (%)								
A49 (Bacterial infection of unspecified site)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
R57 (Shock, not elsewhere classified)	*	*	-	-	-	-	-	-
R96 (Other sudden death, cause unknown)	*	-	*	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
V89 (Motor- or nonmotor-vehicle accident, type of vehicle unspecified)	-	-	-	-	-	-	-	-
Missing	1001 (99.8%)	214 (99.5%)	362 (99.7%)	411 (100.0%)	8 (100.0%)	*	*	*

Causes of death - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
J (Diseases of the respiratory system)	-	-	-	-	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	*	*	*	-	-	-	-	-
U (Codes for special purposes)	-	-	-	-	-	-	-	-
V (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Missing	1001 (99.8%)	214 (99.5%)	362 (99.7%)	411 (100.0%)	8 (100.0%)	*	*	*
Causes of hospitalisation - Level 1; n (%)								
A02.0 (Salmonella enteritis)	-	-	-	-	-	-	-	-
A04.7 (Enterocolitis due to Clostridium difficile)	-	-	-	-	-	-	-	-
A09.0 (Other and unspecified gastroenteritis and colitis of infectious origin)	*	*	-	-	-	-	-	-
A09.9 (Gastroenteritis and colitis of unspecified origin)	-	-	-	-	-	-	-	-
A46.9 (Erysipelas)	-	-	-	-	-	-	-	-
B34.2 (Coronavirus infection, unspecified site, excl. COVID-19)	-	-	-	-	-	-	-	-
B96.5 (Pseudomonas (aeruginosa) as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B97.2 (Coronavirus as the cause of diseases classified to other chapters)	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80.9 (Malignant neoplasm, primary site unspecified)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	*	-	*	-	-	-	-	-

D50.9 (Iron deficiency anaemia, unspecified)	*	-	*	-	-	-	-	-
E08.1 (Diabetes mellitus due to underlying condition with ketoacidosis)	-	-	-	-	-	-	-	-
E10.1 (Diabetes mellitus with ketoacidosis)	*	*	-	-	-	-	-	-
E46 (Unspecified protein-calorie malnutrition)	*	*	-	-	-	-	-	-
E86.0 (Dehydration)	-	-	-	-	-	-	-	-
E87.2 (Acidosis)	-	-	-	-	-	-	-	-
E87.6 (Hypokalemia)	*	-	*	-	-	-	-	-
F31 (Bipolar disorder)	*	-	-	*	-	-	-	-
F98.9 (Unspecified behavioral and emotional disorders with onset usually occurring in childhood and	*	-	*	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40.8 (Other epilepsy)	-	-	-	-	-	-	-	-
G40.9 (Epilepsy, unspecified)	-	-	-	-	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45.9 (Transient cerebral ischaemic attack, unspecified)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	*	*	-	-	-	-	-	-
G83.0 (Diplegia of upper limbs)	*	-	-	*	-	-	-	-
G97.1 (Other reaction to spinal and lumbar puncture)	*	-	*	-	-	-	-	-
H60.9 (Otitis externa, unspecified)	-	-	-	-	-	-	-	-
H65.0 (Acute serous otitis media)	*	-	*	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21.9 (Acute myocardial infarction, unspecified)	-	-	-	-	-	-	-	-
I63.9 (Cerebral infarction, unspecified)	-	-	-	-	-	-	-	-
I70.2 (Atherosclerosis of arteries of extremities)	-	-	-	-	-	-	-	-

I86.3 (Vulval varices)	*	-	*	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-
J03.9 (Acute tonsillitis, unspecified)	*	-	*	-	-	-	-	-
J06.9 (Acute upper respiratory infection, unspecified)	9 (7.0%)	7 (13.7%)	*	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	*	*	-	-	-	-	-	-
J09.9 (Influenza due to identified novel influenza A virus with other manifestations)	-	-	-	-	-	-	-	-
J10.0 (Influenza with pneumonia, seasonal influenza virus identified)	*	*	-	-	-	-	-	-
J12.1 (Respiratory syncytial virus pneumonia)	*	-	*	-	-	-	-	-
J12.8 (Other viral pneumonia)	*	*	-	-	-	-	-	-
J12.9 (Viral pneumonia, unspecified)	*	-	*	-	-	-	-	-
J15.1 (Pneumonia due to Pseudomonas)	*	-	*	-	-	-	-	-
J15.2 (Pneumonia due to staphylococcus)	*	-	*	-	-	-	-	-
J15.6 (Pneumonia due to other Gram-negative bacteria)	*	-	*	-	-	-	-	-
J15.7 (Pneumonia due to Mycoplasma pneumoniae)	-	-	-	-	-	-	-	-
J15.8 (Other bacterial pneumonia)	*	-	*	-	-	-	-	-
J15.9 (Bacterial pneumonia, unspecified)	*	-	*	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	*	*	-	-	-	-	-	-
J16.8 (Pneumonia due to other specified infectious organisms)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	*	-	*	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	*	*	*	-	-	-	-	-

J18.0 (Bronchopneumonia, unspecified)	12 (9.3%)	5 (9.8%)	*	5 (20.0%)	-	-	-	-
J18.9 (Pneumonia, unspecified)	*	*	-	-	-	-	-	-
J20 (Acute bronchitis)	5 (3.9%)	*	*	*	-	-	-	-
J20.9 (Acute bronchitis, unspecified)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	*	*	-	-	-	-	-	-
J21.0 (Acute bronchiolitis due to respiratory syncytial virus)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J35.1 (Hypertrophy of tonsils)	*	-	*	-	-	-	-	-
J35.3 (Hypertrophy of tonsils with hypertrophy of adenoids)	-	-	-	-	-	-	-	-
J69.0 (Pneumonitis due to food and vomit)	*	*	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	*	*	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	*	*	*	-	-	-	-	-
J96.9 (Respiratory failure, unspecified)	*	*	-	-	-	-	-	-
J98.1 (Pulmonary collapse)	-	-	-	-	-	-	-	-
J98.7 (Respiratory infections, not elsewhere classified)	16 (12.4%)	11 (21.6%)	5 (9.6%)	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	*	-	*	-	-	-	-	-
K57.3 (Diverticular disease of large intestine without perforation or abscess)	-	-	-	-	-	-	-	-
K59.0 (Constipation)	-	-	-	-	-	-	-	-
K63.1 (Perforation of intestine (nontraumatic))	-	-	-	-	-	-	-	-

K71.2 (Toxic liver disease with acute hepatitis)	*	-	*	-	-	-	-	-
K80.0 (Calculus of gallbladder with acute cholecystitis)	-	-	-	-	-	-	-	-
K80.1 (Calculus of gallbladder with other cholecystitis)	-	-	-	-	-	-	-	-
K81.0 (Acute cholecystitis)	-	-	-	-	-	-	-	-
K82.9 (Disease of gallbladder, unspecified)	-	-	-	-	-	-	-	-
K92.9 (Disease of digestive system, unspecified)	7 (5.4%)	-	*	5 (20.0%)	-	-	-	-
K94.2 (Gastrostomy complications)	*	*	-	-	-	-	-	-
M41 (Scoliosis)	*	-	*	-	-	-	-	-
M41.4 (Neuromuscular scoliosis)	*	-	-	*	-	-	-	-
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M80.0 (Postmenopausal osteoporosis with pathological fracture)	*	-	-	*	-	-	-	-
M81 (Osteoporosis without pathological fracture)	*	-	*	-	-	-	-	-
M96.6 (Fracture of bone following insertion of orthopaedic implant, joint prosthesis, or bone plate)	*	-	-	-	*	-	-	-
N04 (Nephrotic syndrome)	*	-	*	-	-	-	-	-
N20.1 (Calculus of ureter)	-	-	-	-	-	-	-	-
N32.8 (Other specified disorders of bladder)	-	-	-	-	-	-	-	-
N41.2 (Abscess of prostate)	*	-	-	*	-	-	-	-
N83.2 (Other and unspecified ovarian cysts)	-	-	-	-	-	-	-	-
R00.2 (Palpitations)	-	-	-	-	-	-	-	-
R06 (Abnormalities of breathing)	-	-	-	-	-	-	-	-

R06.0 (Dyspnoea)	-	-	-	-	-	-	-	-
R09.2 (Respiratory arrest)	-	-	-	-	-	-	-	-
R11 (Nausea and vomiting)	*	-	*	-	-	-	-	-
R33 (Retention of urine)	*	-	-	*	-	-	-	-
R41.8 (Other and unspecified symptoms and signs involving cognitive functions and awareness)	*	*	-	-	-	-	-	-
R50.9 (Fever, unspecified)	*	*	*	-	-	-	-	-
R51 (Headache)	*	-	*	-	-	-	-	-
R56.0 (Febrile convulsions)	*	*	-	-	-	-	-	-
R63.3 (Feeding difficulties and mismanagement)	*	-	*	-	-	-	-	-
R63.6 (Insufficient intake of food and water)	-	-	-	-	-	-	-	-
R65.2 (Systemic Inflammatory Response Syndrome of non-infectious origin without organ failure)	-	-	-	-	-	-	-	-
R73.9 (Hyperglycaemia, unspecified)	*	-	*	-	-	-	-	-
S00.9 (Superficial injury of head, part unspecified)	*	*	-	-	-	-	-	-
S36.9 (Injury of unspecified intra-abdominal organ)	*	*	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S72.0 (Fracture of neck of femur)	-	-	-	-	-	-	-	-
S72.4 (Fracture of lower end of femur)	-	-	-	-	-	-	-	-
S73.0 (Dislocation of hip)	*	-	*	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	*	-	-	*	-	-	-	-
S82.9 (Fracture of lower leg, part unspecified)	*	-	-	*	-	-	-	-
T14.2 (Fracture of unspecified body region)	7 (5.4%)	*	-	6 (24.0%)	-	-	-	-

T45.0 (Antiallergic and antiemetic drugs)	-	-	-	-	-	-	-	-
T73.0 (Effects of hunger)	-	-	-	-	-	-	-	-
T81.0 (Haemorrhage and haematoma complicating a procedure, not elsewhere classified)	*	*	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	-	-	-	-	-	-	-	-
Y79.2 (Prosthetic and other implants, materials and accessory orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38.0 (Singleton, born in hospital)	-	-	-	-	-	-	-	-
Z47.8 (Other specified orthopaedic follow-up care)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 2; n (%)								
A02 (Other salmonella infections)	-	-	-	-	-	-	-	-
A04 (Other bacterial intestinal infections)	-	-	-	-	-	-	-	-
A09 (Other gastroenteritis and colitis of infectious and unspecified origin)	*	*	-	-	-	-	-	-
A46 (Erysipelas)	-	-	-	-	-	-	-	-
B34 (Viral infection of unspecified site)	-	-	-	-	-	-	-	-
B96 (Other specified bacterial agents as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B97 (Viral agents as the cause of diseases classified to other chapters)	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-

C80 (Malignant neoplasm, without specification of site)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	*	-	*	-	-	-	-	-
E08 (Diabetes mellitus due to underlying condition)	-	-	-	-	-	-	-	-
E10 (Type 1 diabetes mellitus)	*	*	-	-	-	-	-	-
E46 (Unspecified protein-energy malnutrition)	*	*	-	-	-	-	-	-
E86 (Volume depletion)	-	-	-	-	-	-	-	-
E87 (Other disorders of fluid, electrolyte and acid-base balance)	*	-	*	-	-	-	-	-
F31 (Bipolar affective disorder)	*	-	-	*	-	-	-	-
F98 (Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence)	*	-	*	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40 (Epilepsy)	-	-	-	-	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45 (Transient cerebral ischaemic attacks and related syndromes)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	*	*	-	-	-	-	-	-
G83 (Other paralytic syndromes)	*	-	-	*	-	-	-	-
G97 (Postprocedural disorders of nervous system, not elsewhere classified)	*	-	*	-	-	-	-	-
H60 (Otitis externa)	-	-	-	-	-	-	-	-
H65 (Nonsuppurative otitis media)	*	-	*	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21 (Acute myocardial infarction)	-	-	-	-	-	-	-	-
I63 (Cerebral infarction)	-	-	-	-	-	-	-	-
I70 (Atherosclerosis)	-	-	-	-	-	-	-	-

I86 (Varicose veins of other sites)	*	-	*	-	-	-	-	-
J03 (Acute tonsillitis)	*	-	*	-	-	-	-	-
J06 (Acute upper respiratory infections of multiple and unspecified sites)	9 (7.0%)	7 (13.7%)	*	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	*	*	-	-	-	-	-	-
J10 (Influenza due to identified seasonal influenza virus)	*	*	-	-	-	-	-	-
J12 (Viral pneumonia, not elsewhere classified)	*	*	*	-	-	-	-	-
J15 (Bacterial pneumonia, not elsewhere classified)	7 (5.4%)	-	7 (13.5%)	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	*	*	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	*	-	*	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	17 (13.2%)	7 (13.7%)	5 (9.6%)	5 (20.0%)	-	-	-	-
J20 (Acute bronchitis)	5 (3.9%)	*	*	*	-	-	-	-
J21 (Acute bronchiolitis)	*	*	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J35 (Chronic diseases of tonsils and adenoids)	*	-	*	-	-	-	-	-
J69 (Pneumonitis due to solids and liquids)	*	*	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	*	*	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	*	*	*	-	-	-	-	-
J98 (Other respiratory disorders)	16 (12.4%)	11 (21.6%)	5 (9.6%)	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	*	-	*	-	-	-	-	-
K57 (Diverticular disease of intestine)	-	-	-	-	-	-	-	-

K59 (Other functional intestinal disorders)	-	-	-	-	-	-	-	-
K63 (Other diseases of intestine)	-	-	-	-	-	-	-	-
K71 (Toxic liver disease)	*	-	*	-	-	-	-	-
K80 (Cholelithiasis)	-	-	-	-	-	-	-	-
K81 (Cholecystitis)	-	-	-	-	-	-	-	-
K82 (Other diseases of gallbladder)	-	-	-	-	-	-	-	-
K92 (Other diseases of digestive system)	7 (5.4%)	-	*	5 (20.0%)	-	-	-	-
K94 (Complications of artificial openings of the digestive system)	*	*	-	-	-	-	-	-
M41 (Scoliosis)	*	-	*	*	-	-	-	-
M80 (Osteoporosis with pathological fracture)	*	-	-	*	-	-	-	-
M81 (Osteoporosis without pathological fracture)	*	-	*	-	-	-	-	-
M96 (Postprocedural musculoskeletal disorders, not elsewhere classified)	*	-	-	-	*	-	-	-
N04 (Nephrotic syndrome)	*	-	*	-	-	-	-	-
N20 (Calculus of kidney and ureter)	-	-	-	-	-	-	-	-
N32 (Other disorders of bladder)	-	-	-	-	-	-	-	-
N41 (Inflammatory diseases of prostate)	*	-	-	*	-	-	-	-
N83 (Noninflammatory disorders of ovary, fallopian tube and broad ligament)	-	-	-	-	-	-	-	-
R00 (Abnormalities of heart beat)	-	-	-	-	-	-	-	-
R06 (Abnormalities of breathing)	-	-	-	-	-	-	-	-
R09 (Other symptoms and signs involving the circulatory and respiratory systems)	-	-	-	-	-	-	-	-
R11 (Nausea and vomiting)	*	-	*	-	-	-	-	-
R33 (Retention of urine)	*	-	-	*	-	-	-	-

R41 (Other symptoms and signs involving cognitive functions and awareness)	*	*	-	-	-	-	-	-
R50 (Fever of other and unknown origin)	*	*	*	-	-	-	-	-
R51 (Headache)	*	-	*	-	-	-	-	-
R56 (Convulsions, not elsewhere classified)	*	*	-	-	-	-	-	-
R63 (Symptoms and signs concerning food and fluid intake)	*	-	*	-	-	-	-	-
R65 (Systemic Inflammatory Response Syndrome [SIRS])	-	-	-	-	-	-	-	-
R73 (Elevated blood glucose level)	*	-	*	-	-	-	-	-
S00 (Superficial injury of head)	*	*	-	-	-	-	-	-
S36 (Injury of intra-abdominal organs)	*	*	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S73 (Dislocation, sprain and strain of joint and ligaments of hip)	*	-	*	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	*	-	-	*	-	-	-	-
S82 (Fracture of lower leg, including ankle)	*	-	-	*	-	-	-	-
T14 (Injury of unspecified body region)	7 (5.4%)	*	-	6 (24.0%)	-	-	-	-
T45 (Poisoning by primarily systemic and haematological agents, not elsewhere classified)	-	-	-	-	-	-	-	-
T73 (Effects of other deprivation)	-	-	-	-	-	-	-	-
T81 (Complications of procedures, not elsewhere classified)	*	*	-	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	-	-	-	-	-	-	-	-

Y79 (Orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38 (Liveborn infants according to place of birth and type of delivery)	-	-	-	-	-	-	-	-
Z47 (Other orthopaedic follow-up care)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	*	*	-	-	-	-	-	-
B (Certain infectious and parasitic diseases)	*	-	*	-	-	-	-	-
C (Neoplasms)	-	-	-	-	-	-	-	-
D (Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism)	*	-	*	-	-	-	-	-
E (Endocrine, nutritional and metabolic diseases)	*	*	*	-	-	-	-	-
F (Mental and behavioural disorders)	*	-	*	*	-	-	-	-
G (Diseases of the nervous system)	*	*	*	*	-	-	-	-
H (Diseases of the ear and mastoid process)	*	-	*	-	-	-	-	-
I (Diseases of the circulatory system)	*	-	*	-	-	-	-	-
J (Diseases of the respiratory system)	72 (55.8%)	38 (74.5%)	28 (53.8%)	6 (24.0%)	-	-	-	-
K (Diseases of the digestive system)	10 (7.8%)	*	*	5 (20.0%)	-	-	-	-
M (Diseases of the musculoskeletal system and connective tissue)	5 (3.9%)	-	*	*	*	-	-	-
N (Diseases of the genitourinary system)	*	-	*	*	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	12 (9.3%)	*	7 (13.5%)	*	-	-	-	-
S (Injury, poisoning and certain other consequences of external causes)	5 (3.9%)	*	*	*	-	-	-	-

T (Injury, poisoning and certain other consequences of external causes)	8 (6.2%)	*	-	6 (24.0%)	-	-	-	-
U (Codes for special purposes)	-	-	-	-	-	-	-	-
W (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Y (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Z (Factors influencing health status and contact with health services)	*	-	*	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Incidence rate of each listed comorbidity (per patient-year)								
Diabetes	0	0	0	0	0	*	*	*
Fractures	0	0	0	0	0	*	*	*
Hepatotoxicity	0	0	0	0	0	*	*	*
Non-vertebral fractures	0	0	0	0	0	*	*	*
Osteoporosis	0	0	0	0	0	*	*	*
Pulmonary infections	0	0	0	0	0	*	*	*
Sleep apnea	0	0	0	0	0	*	*	*
Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Mean (SD)	41.7 (25.7)	63.1 (19.9)	49.2 (20.5)	20.8 (19)	-	-	-	-
Median [IQR]	40.1 [18.3, 64.8]	64.5 [46.9, 78.7]	51.1 [36, 67.5]	13.1 [6, 29.7]	-	-	-	-
Missing	897 (89.4%)	195 (90.7%)	315 (86.8%)	373 (90.8%)	8 (100.0%)	*	*	*
Best score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	38.1 (25.9)	60.7 (21.6)	43.8 (20.5)	19.1 (19.6)	-	-	-	-
Median [IQR]	37.5 [15.5, 60.6]	62.8 [46.9, 77.9]	43.4 [26.6, 62]	10.9 [4.8, 27.7]	-	-	-	-
Missing	906 (90.3%)	195 (90.7%)	322 (88.7%)	375 (91.2%)	8 (100.0%)	*	*	*

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Zolgensma SMA Type								
Indicator	Overall (N = 101)	SMA Type 1 (N = 68)	SMA Type 2 (N = 22)	SMA Type 3 (N = 4)	SMA Type 4 (N = 0)	SMA Type Other (N = 1)	SMA Type Presymptomatic (N = 6)	SMA Type Missing (N = 0)
Sex; n (%)								
Female	39 (38.6%)	25 (36.8%)	12 (54.5%)	*	-	-	*	-
Male	62 (61.4%)	43 (63.2%)	10 (45.5%)	*	-	*	5 (83.3%)	-
Missing	-	-	-	-	-	-	-	-
Registry; n (%)								
BE	7 (6.9%)	*	*	-	-	*	-	-
CZ/SK	43 (42.6%)	22 (32.4%)	12 (54.5%)	*	-	-	5 (83.3%)	-
DE/AT	17 (16.8%)	12 (17.6%)	5 (22.7%)	-	-	-	-	-
ES	11 (10.9%)	11 (16.2%)	-	-	-	-	-	-
GB/IE	18 (17.8%)	15 (22.1%)	*	-	-	-	*	-
SE	5 (5.0%)	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Age at symptom onset (years)								
Mean (SD)	0.4 (0.4)	0.2 (0.2)	0.8 (0.3)	*	-	-	-	-
Median [IQR]	0.2 [0.1, 0.5]	0.2 [0.1, 0.3]	0.8 [0.5, 0.8]	*	-	-	-	-
Missing	10 (9.9%)	*	-	-	-	*	6 (100.0%)	-
Reason for genetic testing; n (%)								
Family screening	*	*	-	-	-	-	-	-
Newborn screening	9 (8.9%)	*	-	-	-	*	*	-
No screening	46 (45.5%)	32 (47.1%)	12 (54.5%)	*	-	-	-	-
Prenatal screening	*	-	-	-	-	-	*	-
Missing	44 (43.6%)	31 (45.6%)	10 (45.5%)	*	-	-	*	-
Method used for genetic testing; n (%)								
ddPCR	-	-	-	-	-	-	-	-
DNA Sequencing	-	-	-	-	-	-	-	-
HRM	-	-	-	-	-	-	-	-
MLPA	43 (42.6%)	24 (35.3%)	10 (45.5%)	*	-	*	5 (83.3%)	-

qRT-PCR	*	-	*	-	-	-	-	-
RFLP	-	-	-	-	-	-	-	-
Missing	57 (56.4%)	44 (64.7%)	11 (50.0%)	*	-	-	*	-
SMN1 variant; n (%)								
Compound heterozygous deletion exon 7	*	*	-	-	-	-	-	-
Compound heterozygous substitutions	-	-	-	-	-	-	-	-
Homozygous deletion exon 7	87 (86.1%)	56 (82.4%)	21 (95.5%)	*	-	*	5 (83.3%)	-
Missing	12 (11.9%)	10 (14.7%)	*	-	-	-	*	-
Functional status at genetic report; n (%)								
Non-sitter	12 (11.9%)	6 (8.8%)	6 (27.3%)	-	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Walker	-	-	-	-	-	-	-	-
Missing	89 (88.1%)	62 (91.2%)	16 (72.7%)	*	-	*	6 (100.0%)	-
Achieved motor milestone at genetic report; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	10 (9.9%)	*	6 (27.3%)	-	-	-	-	-
Roll onto side	*	*	-	-	-	-	-	-
Sit without support	-	-	-	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	-	-	-
Missing	89 (88.1%)	62 (91.2%)	16 (72.7%)	*	-	*	6 (100.0%)	-
Best functional status; n (%)								

Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	14 (73.7%)	12 (70.6%)	*	-	-	-	-	-
Yes	5 (26.3%)	5 (29.4%)	-	-	-	-	-	-
1.5 - 2 years								
No	16 (57.1%)	15 (62.5%)	*	-	-	-	-	-
Yes	12 (42.9%)	9 (37.5%)	*	-	-	-	-	-
2 - 6 years								
No	6 (13.3%)	*	*	-	-	-	-	-
Yes	39 (86.7%)	26 (86.7%)	13 (86.7%)	-	-	-	-	-
6 - 11 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for 6MWT								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	100 (99.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best score for 6MWT								
Mean (SD)	*	-	-	*	-	-	-	-

Median [IQR]	*	-	-	*	-	-	-	-
Missing	100 (99.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Most recent score for 6MWT								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-

No	28 (60.9%)	12 (46.2%)	11 (73.3%)	*	-	*	-	-
Yes	18 (39.1%)	14 (53.8%)	*	-	-	-	-	-
6 - 11 years								
No	*	-	*	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Cobb angle value; n (%)								
< 1 month								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
11 - 16 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-

11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at surgery for scoliosis								
Mean (SD)	2.6 (1.4)	2.3 (1.3)	3.8 (1.2)	-	-	*	*	-
Median [IQR]	2.4 [1.3, 3.7]	2.2 [1.2, 3.5]	3.8 [2.9, 4.3]	-	-	*	*	-
Missing	36 (35.6%)	17 (25.0%)	10 (45.5%)	*	-	-	5 (83.3%)	-
Annual number of vertebral fractures by patient reported in cause of hospitalisation or comorbidity								
Mean (SD)	-	-	-	*	-	*	*	-
Median [IQR]	-	-	-	*	-	*	*	-

Missing								
Annual number of non-vertebral fractures by patient reported in cause of hospitalisation or comorbidity								
Mean (SD)	-	-	-	*	-	*	*	-
Median [IQR]	-	-	-	*	-	*	*	-
Missing								
Age at first reported vertebral fracture								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Forced vital capacity percent								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-

Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-	-	-	-	-	-	-	-

Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Forced vital capacity volume								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of any non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	6 (60.0%)	6 (60.0%)	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-

Yes	18 (94.7%)	18 (94.7%)	-	-	-	-	-	-
1.5 - 2 years								
No	7 (36.8%)	7 (36.8%)	-	-	-	-	-	-
Yes	12 (63.2%)	12 (63.2%)	-	-	-	-	-	-
2 - 6 years								
No	6 (24.0%)	6 (24.0%)	-	-	-	-	-	-
Yes	19 (76.0%)	19 (76.0%)	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
At least one episode of full-time non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	10 (100.0%)	10 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	18 (94.7%)	18 (94.7%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	18 (94.7%)	18 (94.7%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	24 (96.0%)	24 (96.0%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	10 (100.0%)	10 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	19 (100.0%)	19 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	19 (100.0%)	19 (100.0%)	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	25 (100.0%)	25 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time sleeping non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	9 (90.0%)	9 (90.0%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	14 (73.7%)	14 (73.7%)	-	-	-	-	-	-
Yes	5 (26.3%)	5 (26.3%)	-	-	-	-	-	-
1.5 - 2 years								
No	16 (84.2%)	16 (84.2%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	20 (80.0%)	20 (80.0%)	-	-	-	-	-	-
Yes	5 (20.0%)	5 (20.0%)	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time non-invasive ventilation episode (years)								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
At least one episode of any invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time awake and sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of part-time sleeping invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								

No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full-time invasive ventilation episode (years)								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Pulmonary infections reported in cause of hospitalisation or as a comorbidity; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (100.0%)	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	8 (100.0%)	5 (100.0%)	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	19 (100.0%)	15 (100.0%)	*	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	11 (100.0%)	6 (100.0%)	*	*	-	-	-	-

Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	26 (100.0%)	17 (100.0%)	7 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of respiratory physiotherapy; n (%)								

< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	7 (70.0%)	7 (70.0%)	-	-	-	-	-	-
1.5 - 2 years								
No	*	*	-	-	-	-	-	-
Yes	5 (55.6%)	5 (55.6%)	-	-	-	-	-	-
2 - 6 years								
No	*	*	-	-	-	-	-	-
Yes	9 (75.0%)	9 (75.0%)	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes	9 (69.2%)	9 (69.2%)	-	-	-	-	-	-
1.5 - 2 years								
No	8 (57.1%)	8 (57.1%)	-	-	-	-	-	-
Yes	6 (42.9%)	6 (42.9%)	-	-	-	-	-	-
2 - 6 years								
No	5 (27.8%)	5 (27.8%)	-	-	-	-	-	-
Yes	13 (72.2%)	13 (72.2%)	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	8 (61.5%)	8 (61.5%)	-	-	-	-	-	-
Yes	5 (38.5%)	5 (38.5%)	-	-	-	-	-	-
1.5 - 2 years								
No	9 (64.3%)	9 (64.3%)	-	-	-	-	-	-
Yes	5 (35.7%)	5 (35.7%)	-	-	-	-	-	-
2 - 6 years								
No	9 (50.0%)	9 (50.0%)	-	-	-	-	-	-
Yes	9 (50.0%)	9 (50.0%)	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-

51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of supplementary feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	9 (69.2%)	9 (69.2%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
1.5 - 2 years								
No	13 (92.9%)	13 (92.9%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	14 (77.8%)	14 (77.8%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one case of gastrostomy; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (100.0%)	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	8 (100.0%)	5 (100.0%)	-	-	-	-	*	-

Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	19 (100.0%)	15 (100.0%)	*	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	11 (100.0%)	6 (100.0%)	*	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	26 (100.0%)	17 (100.0%)	7 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at first gastrostomy (years)								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
At least one hospitalisation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	6 (85.7%)	*	-	-	-	-	*	-
3 - 6 months								
No	12 (75.0%)	10 (71.4%)	-	-	-	-	*	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	16 (50.0%)	13 (48.1%)	*	-	-	-	*	-
Yes	16 (50.0%)	14 (51.9%)	*	-	-	-	-	-
1.5 - 2 years								
No	29 (74.4%)	25 (83.3%)	*	-	-	-	*	-
Yes	10 (25.6%)	5 (16.7%)	*	*	-	-	-	-
2 - 6 years								
No	23 (50.0%)	17 (53.1%)	*	*	-	-	*	-
Yes	23 (50.0%)	15 (46.9%)	6 (60.0%)	*	-	-	-	-
6 - 11 years								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								

J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
R57.9 (Shock, unspecified)	-	-	-	-	-	-	-	-
R57.1 (Hypovolaemic shock)	-	-	-	-	-	-	-	-
R96.0 (Instantaneous death)	-	-	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle accident, traffic)	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Causes of death - Level 2; n (%)								
A49 (Bacterial infection of unspecified site)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
R57 (Shock, not elsewhere classified)	-	-	-	-	-	-	-	-
R96 (Other sudden death, cause unknown)	-	-	-	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
V89 (Motor- or nonmotor-vehicle accident, type of vehicle unspecified)	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Causes of death - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
J (Diseases of the respiratory system)	-	-	-	-	-	-	-	-

R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	-	-	-	-	-	-	-	-
U (Codes for special purposes)	-	-	-	-	-	-	-	-
V (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Causes of hospitalisation - Level 1; n (%)								
A02.0 (Salmonella enteritis)	-	-	-	-	-	-	-	-
A04.7 (Enterocolitis due to Clostridium difficile)	-	-	-	-	-	-	-	-
A09.0 (Other and unspecified gastroenteritis and colitis of infectious origin)	-	-	-	-	-	-	-	-
A09.9 (Gastroenteritis and colitis of unspecified origin)	-	-	-	-	-	-	-	-
A46.9 (Erysipelas)	-	-	-	-	-	-	-	-
B34.2 (Coronavirus infection, unspecified site, excl. COVID-19)	-	-	-	-	-	-	-	-
B96.5 (Pseudomonas (aeruginosa) as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B97.2 (Coronavirus as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80.9 (Malignant neoplasm, primary site unspecified)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	-	-	-	-	-	-	-	-
D50.9 (Iron deficiency anaemia, unspecified)	-	-	-	-	-	-	-	-
E08.1 (Diabetes mellitus due to underlying condition with ketoacidosis)	-	-	-	-	-	-	-	-

E10.1 (Diabetes mellitus with ketoacidosis)	-	-	-	-	-	-	-	-
E46 (Unspecified protein-calorie malnutrition)	-	-	-	-	-	-	-	-
E86.0 (Dehydration)	-	-	-	-	-	-	-	-
E87.2 (Acidosis)	-	-	-	-	-	-	-	-
E87.6 (Hypokalemia)	-	-	-	-	-	-	-	-
F31 (Bipolar disorder)	-	-	-	-	-	-	-	-
F98.9 (Unspecified behavioral and emotional disorders with onset usually occurring in childhood and	-	-	-	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40.8 (Other epilepsy)	-	-	-	-	-	-	-	-
G40.9 (Epilepsy, unspecified)	-	-	-	-	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45.9 (Transient cerebral ischaemic attack, unspecified)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	-	-	-	-	-	-	-	-
G83.0 (Diplegia of upper limbs)	-	-	-	-	-	-	-	-
G97.1 (Other reaction to spinal and lumbar puncture)	-	-	-	-	-	-	-	-
H60.9 (Otitis externa, unspecified)	-	-	-	-	-	-	-	-
H65.0 (Acute serous otitis media)	-	-	-	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21.9 (Acute myocardial infarction, unspecified)	-	-	-	-	-	-	-	-
I63.9 (Cerebral infarction, unspecified)	-	-	-	-	-	-	-	-
I70.2 (Atherosclerosis of arteries of extremities)	-	-	-	-	-	-	-	-
I86.3 (Vulval varices)	-	-	-	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-
J03.9 (Acute tonsillitis, unspecified)	-	-	-	-	-	-	-	-

J06.9 (Acute upper respiratory infection, unspecified)	-	-	-	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	-	-	-	-	-	-	-	-
J09.9 (Influenza due to identified novel influenza A virus with other manifestations)	-	-	-	-	-	-	-	-
J10.0 (Influenza with pneumonia, seasonal influenza virus identified)	-	-	-	-	-	-	-	-
J12.1 (Respiratory syncytial virus pneumonia)	-	-	-	-	-	-	-	-
J12.8 (Other viral pneumonia)	-	-	-	-	-	-	-	-
J12.9 (Viral pneumonia, unspecified)	-	-	-	-	-	-	-	-
J15.1 (Pneumonia due to Pseudomonas)	-	-	-	-	-	-	-	-
J15.2 (Pneumonia due to staphylococcus)	-	-	-	-	-	-	-	-
J15.6 (Pneumonia due to other Gram-negative bacteria)	-	-	-	-	-	-	-	-
J15.7 (Pneumonia due to Mycoplasma pneumoniae)	-	-	-	-	-	-	-	-
J15.8 (Other bacterial pneumonia)	-	-	-	-	-	-	-	-
J15.9 (Bacterial pneumonia, unspecified)	-	-	-	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	-	-	-	-	-	-	-	-
J16.8 (Pneumonia due to other specified infectious organisms)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J18.0 (Bronchopneumonia, unspecified)	-	-	-	-	-	-	-	-
J18.9 (Pneumonia, unspecified)	-	-	-	-	-	-	-	-

J20 (Acute bronchitis)	-	-	-	-	-	-	-	-
J20.9 (Acute bronchitis, unspecified)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	-	-	-	-	-	-	-	-
J21.0 (Acute bronchiolitis due to respiratory syncytial virus)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J35.1 (Hypertrophy of tonsils)	-	-	-	-	-	-	-	-
J35.3 (Hypertrophy of tonsils with hypertrophy of adenoids)	-	-	-	-	-	-	-	-
J69.0 (Pneumonitis due to food and vomit)	-	-	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J96.0 (Acute respiratory failure)	-	-	-	-	-	-	-	-
J96.9 (Respiratory failure, unspecified)	-	-	-	-	-	-	-	-
J98.1 (Pulmonary collapse)	-	-	-	-	-	-	-	-
J98.7 (Respiratory infections, not elsewhere classified)	6 (100.0%)	6 (100.0%)	-	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	-	-	-	-	-	-	-	-
K57.3 (Diverticular disease of large intestine without perforation or abscess)	-	-	-	-	-	-	-	-
K59.0 (Constipation)	-	-	-	-	-	-	-	-
K63.1 (Perforation of intestine (nontraumatic))	-	-	-	-	-	-	-	-
K71.2 (Toxic liver disease with acute hepatitis)	-	-	-	-	-	-	-	-

K80.0 (Calculus of gallbladder with acute cholecystitis)	-	-	-	-	-	-	-	-
K80.1 (Calculus of gallbladder with other cholecystitis)	-	-	-	-	-	-	-	-
K81.0 (Acute cholecystitis)	-	-	-	-	-	-	-	-
K82.9 (Disease of gallbladder, unspecified)	-	-	-	-	-	-	-	-
K92.9 (Disease of digestive system, unspecified)	-	-	-	-	-	-	-	-
K94.2 (Gastrostomy complications)	-	-	-	-	-	-	-	-
M41 (Scoliosis)	-	-	-	-	-	-	-	-
M41.4 (Neuromuscular scoliosis)	-	-	-	-	-	-	-	-
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M80.0 (Postmenopausal osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M81 (Osteoporosis without pathological fracture)	-	-	-	-	-	-	-	-
M96.6 (Fracture of bone following insertion of orthopaedic implant, joint prosthesis, or bone plate)	-	-	-	-	-	-	-	-
N04 (Nephrotic syndrome)	-	-	-	-	-	-	-	-
N20.1 (Calculus of ureter)	-	-	-	-	-	-	-	-
N32.8 (Other specified disorders of bladder)	-	-	-	-	-	-	-	-
N41.2 (Abscess of prostate)	-	-	-	-	-	-	-	-
N83.2 (Other and unspecified ovarian cysts)	-	-	-	-	-	-	-	-
R00.2 (Palpitations)	-	-	-	-	-	-	-	-
R06 (Abnormalities of breathing)	-	-	-	-	-	-	-	-
R06.0 (Dyspnoea)	-	-	-	-	-	-	-	-
R09.2 (Respiratory arrest)	-	-	-	-	-	-	-	-

R11 (Nausea and vomiting)	-	-	-	-	-	-	-	-
R33 (Retention of urine)	-	-	-	-	-	-	-	-
R41.8 (Other and unspecified symptoms and signs involving cognitive functions and awareness)	-	-	-	-	-	-	-	-
R50.9 (Fever, unspecified)	-	-	-	-	-	-	-	-
R51 (Headache)	-	-	-	-	-	-	-	-
R56.0 (Febrile convulsions)	-	-	-	-	-	-	-	-
R63.3 (Feeding difficulties and mismanagement)	-	-	-	-	-	-	-	-
R63.6 (Insufficient intake of food and water)	-	-	-	-	-	-	-	-
R65.2 (Systemic Inflammatory Response Syndrome of non-infectious origin without organ failure)	-	-	-	-	-	-	-	-
R73.9 (Hyperglycaemia, unspecified)	-	-	-	-	-	-	-	-
S00.9 (Superficial injury of head, part unspecified)	-	-	-	-	-	-	-	-
S36.9 (Injury of unspecified intra-abdominal organ)	-	-	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S72.0 (Fracture of neck of femur)	-	-	-	-	-	-	-	-
S72.4 (Fracture of lower end of femur)	-	-	-	-	-	-	-	-
S73.0 (Dislocation of hip)	-	-	-	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	-	-	-	-	-	-	-	-
S82.9 (Fracture of lower leg, part unspecified)	-	-	-	-	-	-	-	-
T14.2 (Fracture of unspecified body region)	-	-	-	-	-	-	-	-
T45.0 (Antiallergic and antiemetic drugs)	-	-	-	-	-	-	-	-
T73.0 (Effects of hunger)	-	-	-	-	-	-	-	-

T81.0 (Haemorrhage and haematoma complicating a procedure, not elsewhere classified)	-	-	-	-	-	-	-	-
U07.1 (COVID-19, virus identified)	-	-	-	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	-	-	-	-	-	-	-	-
Y79.2 (Prosthetic and other implants, materials and accessory orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-
Z38.0 (Singleton, born in hospital)	-	-	-	-	-	-	-	-
Z47.8 (Other specified orthopaedic follow-up care)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 2; n (%)								
A02 (Other salmonella infections)	-	-	-	-	-	-	-	-
A04 (Other bacterial intestinal infections)	-	-	-	-	-	-	-	-
A09 (Other gastroenteritis and colitis of infectious and unspecified origin)	-	-	-	-	-	-	-	-
A46 (Erysipelas)	-	-	-	-	-	-	-	-
B34 (Viral infection of unspecified site)	-	-	-	-	-	-	-	-
B96 (Other specified bacterial agents as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B97 (Viral agents as the cause of diseases classified to other chapters)	-	-	-	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-
C80 (Malignant neoplasm, without specification of site)	-	-	-	-	-	-	-	-
D50 (Iron deficiency anaemia)	-	-	-	-	-	-	-	-

E08 (Diabetes mellitus due to underlying condition)	-	-	-	-	-	-	-	-
E10 (Type 1 diabetes mellitus)	-	-	-	-	-	-	-	-
E46 (Unspecified protein-energy malnutrition)	-	-	-	-	-	-	-	-
E86 (Volume depletion)	-	-	-	-	-	-	-	-
E87 (Other disorders of fluid, electrolyte and acid-base balance)	-	-	-	-	-	-	-	-
F31 (Bipolar affective disorder)	-	-	-	-	-	-	-	-
F98 (Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence)	-	-	-	-	-	-	-	-
F99 (Mental disorder, not otherwise specified)	-	-	-	-	-	-	-	-
G40 (Epilepsy)	-	-	-	-	-	-	-	-
G44 (Other headache syndromes)	-	-	-	-	-	-	-	-
G45 (Transient cerebral ischaemic attacks and related syndromes)	-	-	-	-	-	-	-	-
G81 (Hemiplegia)	-	-	-	-	-	-	-	-
G83 (Other paralytic syndromes)	-	-	-	-	-	-	-	-
G97 (Postprocedural disorders of nervous system, not elsewhere classified)	-	-	-	-	-	-	-	-
H60 (Otitis externa)	-	-	-	-	-	-	-	-
H65 (Nonsuppurative otitis media)	-	-	-	-	-	-	-	-
I10 (Essential (primary) hypertension)	-	-	-	-	-	-	-	-
I21 (Acute myocardial infarction)	-	-	-	-	-	-	-	-
I63 (Cerebral infarction)	-	-	-	-	-	-	-	-
I70 (Atherosclerosis)	-	-	-	-	-	-	-	-
I86 (Varicose veins of other sites)	-	-	-	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-

J06 (Acute upper respiratory infections of multiple and unspecified sites)	-	-	-	-	-	-	-	-
J09 (Influenza due to identified zoonotic or pandemic influenza virus)	-	-	-	-	-	-	-	-
J10 (Influenza due to identified seasonal influenza virus)	-	-	-	-	-	-	-	-
J12 (Viral pneumonia, not elsewhere classified)	-	-	-	-	-	-	-	-
J15 (Bacterial pneumonia, not elsewhere classified)	-	-	-	-	-	-	-	-
J16 (Pneumonia due to other infectious organisms, not elsewhere classified)	-	-	-	-	-	-	-	-
J17 (Pneumonia in diseases classified elsewhere)	-	-	-	-	-	-	-	-
J18 (Pneumonia, organism unspecified)	-	-	-	-	-	-	-	-
J20 (Acute bronchitis)	-	-	-	-	-	-	-	-
J21 (Acute bronchiolitis)	-	-	-	-	-	-	-	-
J22 (Unspecified acute lower respiratory infection)	-	-	-	-	-	-	-	-
J35 (Chronic diseases of tonsils and adenoids)	-	-	-	-	-	-	-	-
J69 (Pneumonitis due to solids and liquids)	-	-	-	-	-	-	-	-
J80 (Adult respiratory distress syndrome)	-	-	-	-	-	-	-	-
J96 (Respiratory failure, not elsewhere classified)	-	-	-	-	-	-	-	-
J98 (Other respiratory disorders)	6 (100.0%)	6 (100.0%)	-	-	-	-	-	-
K29 (Gastritis and duodenitis)	-	-	-	-	-	-	-	-
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)	-	-	-	-	-	-	-	-
K57 (Diverticular disease of intestine)	-	-	-	-	-	-	-	-
K59 (Other functional intestinal disorders)	-	-	-	-	-	-	-	-
K63 (Other diseases of intestine)	-	-	-	-	-	-	-	-

K71 (Toxic liver disease)	-	-	-	-	-	-	-	-
K80 (Cholelithiasis)	-	-	-	-	-	-	-	-
K81 (Cholecystitis)	-	-	-	-	-	-	-	-
K82 (Other diseases of gallbladder)	-	-	-	-	-	-	-	-
K92 (Other diseases of digestive system)	-	-	-	-	-	-	-	-
K94 (Complications of artificial openings of the digestive system)	-	-	-	-	-	-	-	-
M41 (Scoliosis)	-	-	-	-	-	-	-	-
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-
M81 (Osteoporosis without pathological fracture)	-	-	-	-	-	-	-	-
M96 (Postprocedural musculoskeletal disorders, not elsewhere classified)	-	-	-	-	-	-	-	-
N04 (Nephrotic syndrome)	-	-	-	-	-	-	-	-
N20 (Calculus of kidney and ureter)	-	-	-	-	-	-	-	-
N32 (Other disorders of bladder)	-	-	-	-	-	-	-	-
N41 (Inflammatory diseases of prostate)	-	-	-	-	-	-	-	-
N83 (Noninflammatory disorders of ovary, fallopian tube and broad ligament)	-	-	-	-	-	-	-	-
R00 (Abnormalities of heart beat)	-	-	-	-	-	-	-	-
R06 (Abnormalities of breathing)	-	-	-	-	-	-	-	-
R09 (Other symptoms and signs involving the circulatory and respiratory systems)	-	-	-	-	-	-	-	-
R11 (Nausea and vomiting)	-	-	-	-	-	-	-	-
R33 (Retention of urine)	-	-	-	-	-	-	-	-
R41 (Other symptoms and signs involving cognitive functions and awareness)	-	-	-	-	-	-	-	-

R50 (Fever of other and unknown origin)	-	-	-	-	-	-	-	-
R51 (Headache)	-	-	-	-	-	-	-	-
R56 (Convulsions, not elsewhere classified)	-	-	-	-	-	-	-	-
R63 (Symptoms and signs concerning food and fluid intake)	-	-	-	-	-	-	-	-
R65 (Systemic Inflammatory Response Syndrome [SIRS])	-	-	-	-	-	-	-	-
R73 (Elevated blood glucose level)	-	-	-	-	-	-	-	-
S00 (Superficial injury of head)	-	-	-	-	-	-	-	-
S36 (Injury of intra-abdominal organs)	-	-	-	-	-	-	-	-
S72 (Fracture of femur)	-	-	-	-	-	-	-	-
S73 (Dislocation, sprain and strain of joint and ligaments of hip)	-	-	-	-	-	-	-	-
S79 (Other and unspecified injuries of hip and thigh)	-	-	-	-	-	-	-	-
S82 (Fracture of lower leg, including ankle)	-	-	-	-	-	-	-	-
T14 (Injury of unspecified body region)	-	-	-	-	-	-	-	-
T45 (Poisoning by primarily systemic and haematological agents, not elsewhere classified)	-	-	-	-	-	-	-	-
T73 (Effects of other deprivation)	-	-	-	-	-	-	-	-
T81 (Complications of procedures, not elsewhere classified)	-	-	-	-	-	-	-	-
U07 (Emergency use of U07)	-	-	-	-	-	-	-	-
W79 (Inhalation and ingestion of food causing obstruction of respiratory tract)	-	-	-	-	-	-	-	-
Y79 (Orthopedic devices associated with adverse incidents)	-	-	-	-	-	-	-	-

Z38 (Liveborn infants according to place of birth and type of delivery)	-	-	-	-	-	-	-	-
Z47 (Other orthopaedic follow-up care)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation - Level 3; n (%)								
A (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
B (Certain infectious and parasitic diseases)	-	-	-	-	-	-	-	-
C (Neoplasms)	-	-	-	-	-	-	-	-
D (Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism)	-	-	-	-	-	-	-	-
E (Endocrine, nutritional and metabolic diseases)	-	-	-	-	-	-	-	-
F (Mental and behavioural disorders)	-	-	-	-	-	-	-	-
G (Diseases of the nervous system)	-	-	-	-	-	-	-	-
H (Diseases of the ear and mastoid process)	-	-	-	-	-	-	-	-
I (Diseases of the circulatory system)	-	-	-	-	-	-	-	-
J (Diseases of the respiratory system)	6 (100.0%)	6 (100.0%)	-	-	-	-	-	-
K (Diseases of the digestive system)	-	-	-	-	-	-	-	-
M (Diseases of the musculoskeletal system and connective tissue)	-	-	-	-	-	-	-	-
N (Diseases of the genitourinary system)	-	-	-	-	-	-	-	-
R (Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified)	-	-	-	-	-	-	-	-
S (Injury, poisoning and certain other consequences of external causes)	-	-	-	-	-	-	-	-
T (Injury, poisoning and certain other consequences of external causes)	-	-	-	-	-	-	-	-

U (Codes for special purposes)	-	-	-	-	-	-	-	-
W (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Y (External causes of morbidity and mortality)	-	-	-	-	-	-	-	-
Z (Factors influencing health status and contact with health services)	-	-	-	-	-	-	-	-
missing	-	-	-	-	-	-	-	-
Incidence rate of each listed comorbidity (per patient-year)								
Diabetes	0	0	0	*	-	*	0	-
Fractures	0	0	0	*	-	*	0	-
Hepatotoxicity	0	0	0	*	-	*	0	-
Non-vertebral fractures	0	0	0	*	-	*	0	-
Osteoporosis	0	0	0	*	-	*	0	-
Pulmonary infections	0	0	0	*	-	*	0	-
Sleep apnea	0	0	0	*	-	*	0	-
Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Most recent score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	*	*	-	-	-	-	-	-

Median [IQR]	*	*	-	-	-	-	-	-
Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Score for Belgium ACTIVLIM PRO at genetic report date								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best score for Belgium ACTIVLIM PRO								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Most recent score for Belgium ACTIVLIM PRO								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								

