	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	*	-	*	-	-	-	-	-			

			Never	Treated   SMA Type	e			
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	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%)

			Never	Treated   SMA Type	e			
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)
Best functional status; n	Overall (24 017)	(24 101)	(11 201)	(11 2))			(1, 1)	(14 10)
Non-sitter	8 (0.9%)	-	8 (2.2%)	-	-	-	-	-
Missing	839 (99.1%)	154 (100.0%)	353 (97.8%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Best achieved motor milestone; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	*	-	*	-	-	-	-	-
Roll onto side	7 (0.8%)	-	7 (1.9%)	-	-	-	-	-
Sit without support	-	-	-	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance	-	-	-	-	-	-	-	-
Walk without assistance	-	-	-	-	-	_	-	-
Missing	839 (99.1%)	154 (100.0%)	353 (97.8%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Best functional status before treatment; n (%)								
Non-sitter	-	-	-	-	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Walker	-	-	-	-	-	-	-	-
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Best functional status after treatment; n (%)								
Non-sitter	-	-	-	-	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Walker	_	-	-	-	-	-	-	-

			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	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Best achieved motor milestone before treatment; n (%)								
Climb stairs	-	-	-	-	-	_	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
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	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Best achieved motor milestone after treatment;								
Climb stairs	-	-	-	-	-	_	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
Roll onto side	-	-	-	-	-	-	-	-
Sit without support	-	-	-	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-

			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)
Walk 10 metres without assistance	-	-	-	-	-	-	-	-
Walk with assistance		-	_	<u> -</u>	-	-	-	-
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]	*	*	*	<u> -</u>	-	-	-	-
Missing		-	_	<u> -</u>	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	-	*	*	-	-	-	-
Median [IQR]	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	101.8 (9.8)	*	*	*	-	-	-	*
Median [IQR]	100 [97.2, 105]	*	*	*	-	_	-	*

	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)	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]	*	-	-	-			

			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	-	-	-	_	-	-	-	-
> 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)	*	*	*	*	-	-	-	-

	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	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]	*	-	_	_			

			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	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%)	*	*	-	-	-	_	-

			Never	Treated   SMA Type	e			
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)
1.5 - 2 years								
No	24 (63.2%)	10 (71.4%)	14 (58.3%)	-	-	-	-	1
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%)	-	-	_	-

			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	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	-	-	<u></u>	-	-	-	-	-
1.5 - 2 years								
•								
>1	-	-	-	<u> -</u>	-	-	-	-
0	51 (100.0%)	22 (100.0%)	26 (100.0%)	*	-	-	-	*

			Never	Treated   SMA Type	e			
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	-	-	-	-	-	-	-	-
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	*	-	-	-	*	_	-	-

			Never	Treated   SMA Type	e			
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								
>1	9 (11.5%)	-	-	9 (15.5%)	-	-	-	-
0	67 (85.9%)	-	15 (100.0%)	47 (81.0%)	*	*	-	-
1	*	-	-	*	-	-	-	-
> 60 years								
>1	*	-	-	*	-	-	-	-
0	34 (91.9%)	-	*	24 (92.3%)	5 (100.0%)	*	-	*
1	*	_	-	*	-	*	_	-
Closest score for CHOP-INTEND								
Mean (SD)	25.8 (15.2)	*	*	*	-	*	-	-
Median [IQR]	27 [13, 40]	*	*	*	-	*	-	-
Missing	838 (98.9%)	150 (97.4%)	358 (99.2%)	298 (99.7%)	13 (100.0%)	*	*	16 (100.0%)
Best score for CHOP-INTEND								
Mean (SD)	28.3 (18.5)	*	*	*	-	*	-	-
Median [IQR]	27 [13, 42]	*	*	*	-	*	-	-
Missing	838 (98.9%)	150 (97.4%)	358 (99.2%)	298 (99.7%)	13 (100.0%)	*	*	16 (100.0%)
Most recent score for CHOP-INTEND								
< 1 month								
Mean (SD)	-	-	_	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
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 - 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)		-	-	-	-	<u> -</u>	-	-		
Median [IQR]		-	-	-	-	<u> -</u>	-	-		
Missing	_	-	_	_	_	_	-	-		
11 - 16 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	_	-	-	_	-		
-										
Missing	-	-	-	-	-	<u> -</u>	-	-		
16 - 21 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	<u> </u> -	-	-		
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)		
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 HFMS(- E)										
Mean (SD)	33.9 (26.2)	*	*	38.5 (23.7)	-	-	-	*		
Median [IQR]	36 [5, 60]	*	*	51 [14.5, 60]	-	-	-	*		
Missing	828 (97.8%)	153 (99.4%)	359 (99.4%)	284 (95.0%)	13 (100.0%)	*	*	15 (93.8%)		
Best score for HFMS(-E)										
Mean (SD)	34.2 (26.5)	*	*	38.8 (23.9)	-	-	-	*		
Median [IQR]	36 [5, 60]	*	*	51 [14.5, 60]	-	-	-	*		
Missing	828 (97.8%)	153 (99.4%)	359 (99.4%)	284 (95.0%)	13 (100.0%)	*	*	15 (93.8%)		
Most recent score for HFMS(-E)										
< 1 month										

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	e			
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)		
Median [IQR]	*	-	-	*	-	-	-	-		
Missing	-	_	-	-	-	-	-	-		
> 60 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
Closest score for HINE-2										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)		
Best score for HINE-2										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)		
Most recent score for HINE-2										
< 1 month										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)		
Closest score for MFM32										
Mean (SD)	*	-	-	*	-	-	-	*		
Median [IQR]	*	-	-	*	-	-	-	*		
Missing	845 (99.8%)	154 (100.0%)	361 (100.0%)	298 (99.7%)	13 (100.0%)	*	*	15 (93.8%)		
Best score for MFM32										
Mean (SD)	72.3 (26.4)	-	*	*	-	-	-	*		
Median [IQR]	83 [61, 93]	-	*	*	-	-	-	*		
Missing	841 (99.3%)	154 (100.0%)	360 (99.7%)	295 (98.7%)	13 (100.0%)	*	*	15 (93.8%)		
Most recent score for MFM32										

			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 month								
Mean (SD)	-	-	-	_	-	_	-	-
Median [IQR]	-	-	-	_	-	_	-	-
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)
Closest score for 6MWT								
Mean (SD)	392 (188.4)	-	-	380.4 (193.8)	-	-	-	*
Median [IQR]	456 [283, 506.5]	-	-	435.5 [229.5, 505]	-	-	-	*
Missing	836 (98.7%)	154 (100.0%)	361 (100.0%)	289 (96.7%)	13 (100.0%)	*	*	15 (93.8%)
Best score for 6MWT								
Mean (SD)	423.2 (202.3)	-	-	411.6 (206.4)	-	-	-	*
Median [IQR]	456 [276, 598]	-	-	435.5 [251, 599.8]	-	-	-	*
Missing	834 (98.5%)	154 (100.0%)	361 (100.0%)	287 (96.0%)	13 (100.0%)	*	*	15 (93.8%)
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]	-	-	-		-		-	-

	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)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
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)			
41 - 51 years											
Mean (SD)	*	-	-	*	-	-	-	-			
Median [IQR]	*	1	-	*	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
51 - 61 years											
Mean (SD)	*	-	-	*	-	-	-	-			
Median [IQR]	*	-	-	*	-	-	-	-			
Missing	-	1	-	-	-	-	-	-			
> 60 years											
Mean (SD)	-	1	-	-	-	-	-	-			
Median [IQR]	-	1	-	-	-	-	-	-			
Missing	-	1	-	-	-	-	-	-			
Change between scores in HFSM-E in consecutive age classes											
< 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]	-		-	-	-	-	-	-			

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)	*	-	*	*	-	-	-	-	
Median [IQR]	*	-	*	*	-	-	-	-	
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)		
41 - 51 years										
Mean (SD)	*	-	-	*	-	-	-	-		
Median [IQR]	*	-	-	*	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
51 - 61 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
> 60 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
Change between scores in RULM in consecutive age classes										
< 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]	-	-	-	-	-	-	-	-		

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)	*	-	-	*	-	-	-	-	
Median [IQR]	*	-	-	*	-	-	-	-	
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)		
41 - 51 years										
Mean (SD)	*	-	-	*	-	-	-	-		
Median [IQR]	*	-	-	*	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
51 - 61 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
> 60 years										
Mean (SD)	-	-	-	-	-	-	-	-		
Median [IQR]	-	-	-	-	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
Change between scores in 6MWT in consecutive age classes										
< 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]	-	-	-	-	-	-	-	-		

	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)			
Age at report of (first) best HINE-2 score	(	(2. 25.1)	(=: 552)	(** =33)	(* 25)			(11 20)			
Mean (SD)	-	-	-	-	-	-	-	-			
Median [IQR]	-	-	-	-	-	-	-	-			
Missing	847 (100.0%)	154 (100.0%)	361 (100.0%)	299 (100.0%)	13 (100.0%)	*	*	16 (100.0%)			
Age at report of (first) best MFM32 score											
Mean (SD)	23.6 (18.4)	-	*	*	-	-	-	*			
Median [IQR]	22 [10.5, 24]	-	*	*	-	_	-	*			
Missing	841 (99.3%)	154 (100.0%)	360 (99.7%)	295 (98.7%)	13 (100.0%)	*	*	15 (93.8%)			
Age at report of (first) 6MWT best score											
Mean (SD)	29.4 (19.1)	-	-	31.4 (18.6)	-	-	-	*			
Median [IQR]	24.7 [14.1, 43.4]	-	-	27.2 [15.5, 45.4]	-	-	-	*			
Missing	834 (98.5%)	154 (100.0%)	361 (100.0%)	287 (96.0%)	13 (100.0%)	*	*	15 (93.8%)			
Ever diagnosed with 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											

	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)			
Cobb angle value; n (%)											
< 1 month											
<30°	-	-	-	-	-	-	-	-			
>45°	-	-	-	-	-	-	-	-			
30-45°	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
1 - 3 months											
<30°	-	-	-	-	-	-	-	-			
>45°	-	-	-	-	-	-	-	-			
30-45°	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
3 - 6 months											
200											
<30°	-	-	-	-	-	-	-	-			
>45°	-	-	-	-	-	-	-	-			
30-45°	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
6 - 18 months											
<30°	-	-	-	-	-	-	-	-			
>45°	-	-	<del>-</del>	-	<del>-</del>	-	-	-			
30-45°	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
1.5 - 2 years											
<30°	-	-	-	-	-	-	-	-			
>45°	-	-	-	-	-	-	-	-			
30-45°	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
2 - 6 years											

			Never '	Freated   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)
<30°	-	-	-	-	-	-	-	-
>45°	*	*	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
<30°	-	-	-	-	-	-	-	-
>45°	*	-	*	*	-	-	-	-
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°	5 (83.3%)	-	*	*	-	-	-	-
30-45°	*	-	*	-	-	-	-	-
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)		
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)			
Yes	-	-	-	-	-	-	-	-			
3 - 6 months											
No	11 (100.0%)	11 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
6 - 18 months											
No	33 (100.0%)	27 (100.0%)	6 (100.0%)	-	-	-	_	-			
Yes	-	-	-	-	-	-	-	-			
1.5 - 2 years											
No	20 (100.0%)	9 (100.0%)	10 (100.0%)	-	-	-	-	*			
Yes	-	-	-	-	-	-	-	-			
2 - 6 years											
No	105 (97.2%)	39 (97.5%)	54 (96.4%)	11 (100.0%)	-	-	-	*			
Yes	*	*	*	_	_	_	_	-			
6 - 11 years											
No	67 (81.7%)	11 (100.0%)	38 (73.1%)	18 (94.7%)	-	-	-	-			
Yes	15 (18.3%)	-	14 (26.9%)	*	-	-	-	-			
11 - 16 years											
No	31 (43.1%)	*	14 (31.1%)	13 (68.4%)	-	-	-	*			
Yes	41 (56.9%)	*	31 (68.9%)	6 (31.6%)	-	-	-	-			
16 - 21 years											
No	17 (30.9%)	*	*	13 (59.1%)	-	-	-	-			
Yes	38 (69.1%)	-	29 (96.7%)	9 (40.9%)	-	-	-	-			
21 - 31 years											
No	42 (42.4%)	*	17 (27.0%)	22 (66.7%)	-	-	-	-			
Yes	57 (57.6%)	-	46 (73.0%)	11 (33.3%)	-	-	-	-			
31 - 41 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)			
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								<b>,</b> , , , , , , , , , , , , , , , , , ,			
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	e			
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 7	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								
Mean (SD)	71.6 (15.8)	-	-	*	*	*	-	-
Median [IQR]	75 [66.5, 78.5]	-	-	*	*	*	-	-
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)	-	-	-	-	-	-	-	-
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)	*	-	-	*	-	-	-	-				
Median [IQR]	*	-	-	*	-	-	-	-				
Missing	8 (88.9%)	-	5 (100.0%)	*	-	-	-	-				
11 - 16 years												
Mean (SD)	*	-	-	*	-	_	-	-				
Median [IQR]	*	-	-	*	-	-	-	1				
Missing	12 (92.3%)	*	9 (100.0%)	*	-	-	-	1				
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)			
Missing	*	-	-	*	-	-	-	-			
> 60 years											
Mean (SD)	2.3 (1.2)	-	-	*	*	*	-	-			
Median [IQR]	2.3 [1.9, 2.8]	-	-	*	*	*	-	-			
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	*	*	-	*	-	-	-	-			
Yes	*	*	*	-	-	-	-	-			
6 - 11 years											
No	*	-	*	*	-	-	-	-			
Yes	*	*	*	-	-	-	-	-			
11 - 16 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)
No	*	-	-	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
16 - 21 years								
No	11 (40.7%)	-	*	6 (75.0%)	*	-	-	-
Yes	16 (59.3%)	*	12 (75.0%)	*	-	-	-	-
21 - 31 years								
No	20 (44.4%)	-	9 (31.0%)	11 (84.6%)	-	-	-	-
Yes	25 (55.6%)	*	20 (69.0%)	*	-	-	-	-
31 - 41 years								
No	18 (56.2%)	-	5 (31.2%)	13 (81.2%)	-	-	-	-
Yes	14 (43.8%)	-	11 (68.8%)	*	-	-	-	-
41 - 51 years								
No	15 (65.2%)	-	*	12 (80.0%)	-	-	-	-
Yes	8 (34.8%)	-	5 (62.5%)	*	-	-	-	-
51 - 61 years								
No	21 (80.8%)	-	*	18 (94.7%)	*	-	-	-
Yes	5 (19.2%)	-	*	*	-	-	-	-
> 60 years								
No	13 (100.0%)	-	*	9 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of any non-invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	_	_	_	_	-	-
1 - 3 months								

	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											
N	15 (02 00/)	12 (02 00/)	*								
No V	15 (93.8%)	13 (92.9%)	<u> </u>	-	<del> -</del>	-	-	-			
Yes		<u> </u>	<del>-</del>	-	<del> -</del>	-	-	-			
1.5 - 2 years	10 (05 00/)	14 (02 20/)	5 (100 00/)		1						
No	19 (95.0%)	14 (93.3%)	5 (100.0%)	- 	- 	-	<del>-</del>	-			
Yes		<u> </u>	<del>-</del>	-	<del> -</del>	-	-	-			
2 - 6 years	20 (79 40/)	17 (60.00/)	12 (100 00/)								
No	29 (78.4%)	17 (68.0%)	12 (100.0%)	-	- 	-	-	-			
Yes	8 (21.6%)	8 (32.0%)	-	-	-	-	-	-			
6 - 11 years	26 (52 00)	0 (20 10()	17 (62 00()								
No	26 (52.0%)	9 (39.1%)	17 (63.0%)	- 	- 	-	<del>-</del>	-			
Yes	24 (48.0%)	14 (60.9%)	10 (37.0%)	-	- 	-	-	-			
11 - 16 years	22 (59 20/)	9 (52 20/)	24 ((1.50/)	+	1	+					
No V	32 (58.2%)	8 (53.3%)	24 (61.5%)	*	<del>-</del>	-	-	<del>-</del>			
Yes	23 (41.8%)	7 (46.7%)	15 (38.5%)	T	<del> -</del>	-	-	<del>-</del>			
16 - 21 years	21 (22 00/)	*	16 (21 40/)	*		+					
No V	21 (32.8%)		16 (31.4%)	7	<del>-</del>	-	-	<del>-</del>			
Yes	43 (67.2%)	8 (66.7%)	35 (68.6%)	-	- 	-	-	<del>-</del>			
21 - 31 years	17 (20, 20)	*	15 (20 42)								
No	17 (29.8%)	*	15 (29.4%)	-	-	-	<u> </u> -	-			

	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	e			
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	*	*	-	-	-	-	-	-
2 - 6 years								
No	35 (94.6%)	23 (92.0%)	12 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	46 (92.0%)	20 (87.0%)	26 (96.3%)	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
11 - 16 years								
No	53 (96.4%)	14 (93.3%)	38 (97.4%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
16 - 21 years								
No	61 (95.3%)	10 (83.3%)	50 (98.0%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	56 (98.2%)	5 (100.0%)	50 (98.0%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
31 - 41 years								
No	26 (86.7%)	*	22 (91.7%)	*	-	-	-	-
Yes	*	-	*	*	-	-	-	-
41 - 51 years								
No	26 (100.0%)	-	16 (100.0%)	10 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	13 (92.9%)	-	7 (100.0%)	6 (85.7%)	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	5 (100.0%)	-	*	*	-	-	-	-
Yes	-	_	-	-	-	-	-	<u>-</u>

	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 T	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)			
Yes	-	-	-	-	-	_	-	-			
16 - 21 years											
No	60 (93.8%)	12 (100.0%)	47 (92.2%)	*	-	-	-	-			
Yes	*	-	*	-	-	-	-	-			
21 - 31 years											
No	53 (93.0%)	5 (100.0%)	47 (92.2%)	*	-	-	-	-			
Yes	*	-	*	-	-	-	-	-			
31 - 41 years											
No	29 (96.7%)	*	23 (95.8%)	5 (100.0%)	-	-	-	-			
Yes	*	-	*	-	-	-	-	-			
41 - 51 years											
No	25 (96.2%)	-	16 (100.0%)	9 (90.0%)	-	-	-	-			
Yes	*	-	_	*	-	-	-	-			
51 - 61 years											
No	13 (92.9%)	-	7 (100.0%)	6 (85.7%)	-	-	-	-			
Yes	*	-	-	*	-	-	-	-			
> 60 years											
No	5 (100.0%)	-	*	*	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
Age at start of first full- time non-invasive ventilation episode (years)											
Mean (SD)	16.2 (16)	*	*	*	-	-	-	-			
Median [IQR]	13 [5.6, 18.1]	*	*	*	-	-	-	-			
Missing	840 (99.2%)	152 (98.7%)	357 (98.9%)	298 (99.7%)	13 (100.0%)	*	*	16 (100.0%)			
At least one episode of any invasive ventilation; n (%)											
< 1 month											
No	-	-	-	-	-	-	-	-			
Yes	-	-	_	_	_	-	-	-			

			Never 7	Freated   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	*	*	-	-	-	-	-	-
V	*	*						
Yes	*	T	-	-	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	<u> </u> -	-

	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)		
2 - 6 years										
No	7 (58.3%)	7 (58.3%)	-	-	-	-	-	-		
Yes	5 (41.7%)	5 (41.7%)	-	-	-	-	-	-		
6 - 11 years										
No	*	*	-	-	-	-	-	-		
Yes	8 (88.9%)	8 (88.9%)	-	-	-	-	-	-		
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	-	-	-	-	-	-	-	-		

			Never T	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 (%)	(	(* == )		(- =22)	(= ===)		(** 2)	(1. 10)
< 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 T	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 7	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	-	-	-	-	-	_	-	_
51 - 61 years								
No	*	-	-	*	-	-	-	_
> 60 years								
No	*	-	-	*	-	-	-	-
Age at start of first full- time invasive ventilation episode (years)								
Mean (SD)	8.3 (13.4)	*	*	*	-	-	-	-
Median [IQR]	3 [0.5, 6.6]	*	*	*	-	-	-	-
Missing	840 (99.2%)	150 (97.4%)	359 (99.4%)	298 (99.7%)	13 (100.0%)	*	*	16 (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								

			Never 7	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 ,	*	*	*	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No ,	*	*	-	-	-	-	-	-
Yes -	-	-	-	-	-	-	-	-
11 - 16 years								
No 8	8 (100.0%)	*	6 (100.0%)	*	-	-	-	-
Yes -		-	-	-	-	-	-	-
16 - 21 years								
No	7 (87.5%)	-	5 (100.0%)	*	-	-	-	-
Yes	*	-	-	*	-	-	-	-
21 - 31 years								
No 2	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 2	21 (100.0%)	-	5 (100.0%)	14 (100.0%)	*	-	-	-
Yes -	-	-	-	-	-	-	-	-
> 60 years								
No 3	7 (100.0%)	-	*	*	-	*	-	-
Yes -	<u></u>		-	-	-	-	-	

	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 respiratory physiotherapy; n (%)								, , , , ,			
< 1 month											
No	-	-	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	_			
1 - 3 months											
No	-	-	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
3 - 6 months											
No	-	-	-	-	-	-	-	1			
Yes	-	-	-	-	-	-	-	1			
6 - 18 months											
No	*	*	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
1.5 - 2 years											
No	*	*	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
2 - 6 years											
No	*	*	*	-	-	-	-	-			
Yes	*	*	-	-	-	-	-	-			
6 - 11 years											
No	-	-	-	-	-	-	-	-			
Yes	5 (100.0%)	*	*	-	-	-	-	_			
11 - 16 years											
No	*	-	*	*	-	-	-	-			
Yes	*	*	-	*	-	-	-	-			
16 - 21 years											

			Never T	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	5 (50.0%)	-	*	*	-	-	-	-
Yes	5 (50.0%)	-	*	*	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
Yes	14 (77.8%)	-	12 (75.0%)	*	-	-	-	-
31 - 41 years								
No	*	-	*	*	-	-	-	-
Yes	6 (66.7%)	-	6 (75.0%)	-	-	-	-	-
41 - 51 years								
No	*	-	*	*	-	-	-	-
Yes	5 (62.5%)	-	*	*	-	-	-	-
51 - 61 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	1
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	*	-	-	-	-	*	-	-
3 - 6 months								
No	6 (100.0%)	5 (100.0%)	-	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								

			Never	Treated   SMA Type	2			
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	*	*	-	- 	-	-	-	<u>-</u>
6 - 11 years	20 (02 50()	22 (05 00()	5 (02 20()	*				
No	29 (93.5%)	23 (95.8%)	5 (83.3%)	*	-	-	-	-
Yes	*	*	1	- 	-	-	-	-
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 '	Freated   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)
11 - 16 years								
No	25 (92.6%)	10 (90.9%)	14 (93.3%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
16 - 21 years								
No	14 (73.7%)	5 (71.4%)	9 (75.0%)	-	-	-	-	-
Yes	5 (26.3%)	*	*	-	-	-	-	-
21 - 31 years								
No	12 (70.6%)	*	10 (71.4%)	-	-	-	-	-
Yes	5 (29.4%)	*	*	_	-	-	-	-
31 - 41 years								
No	7 (70.0%)	*	6 (66.7%)	-	-	-	-	-
Yes	*	_	*	-	-	-	-	-
41 - 51 years								
No	*	_	-	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
51 - 61 years								
No	<u> -</u>	-	-	-	-	-	-	_
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of supplementary feeding tube usage; n (%)								
< 1 month								
No	-	_	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								

			Never	Treated   SMA Type	2			
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	6 (100.0%)	5 (100.0%)	-	-	-	*	_	-
Yes	-	-	-	-	-	-	-	1
6 - 18 months								
No	27 (100.0%)	24 (100.0%)	*	-	-	*	-	1
Yes	-	-	-	-	-	-	-	1
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	31 (100.0%)	24 (100.0%)	6 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	26 (96.3%)	11 (100.0%)	14 (93.3%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
16 - 21 years								
No	17 (89.5%)	7 (100.0%)	10 (83.3%)	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
21 - 31 years								
No	14 (82.4%)	*	12 (85.7%)	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
31 - 41 years								
No	10 (100.0%)	*	9 (100.0%)	-	-	-	-	-
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%)	*	-	-	-	1			
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	-	-	<u> </u> -	-	-	-	-	-			
> 60 years											
No	7 (100.0%)	-	*	*	-	*	-	-			
Yes	<u> </u>	-	-	-	-	-	-	-			
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)			
Missing	846 (99.9%)	154 (100.0%)	360 (99.7%)	299 (100.0%)	13 (100.0%)	*	*	16 (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	*	*	_	_	_	_	_	_			
Yes	*	*	-	-	-	-	_	-			
6 - 11 years											
No	*	*	*	_	_	-	-	-			
Yes	_	_	-	_	_	-	-	-			
11 - 16 years											
No	*	_	-	*	_	-	-	-			
Yes	6 (66.7%)	_	6 (100.0%)	-	-	-	-	-			
16 - 21 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)
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)	_	1_	_	_
Median [IQR]	96.5 [12.2, 290.2]	11.5 [5.2, 39.8]	219 [156, 515]	532 [393.5, 588.5]	_	1_	_	_
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 (%)	(22.270)	150 (00.570)	310 (70.770)	272 (71.170)	13 (100.070)			10 (100.070)
A49.9 (Bacterial infection, unspecified)	*	-	*	-	-	-	-	-

			Never	Treated   SMA Type	2			
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)	<u> </u>	-	<u>  "</u>	-	-	-	-	-
V89.2 (Person injured in unspecified motor-vehicle								
accident, traffic)	*	_		*			<u> </u>	
- ´			-		-	-		
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		<u>-</u>		<u> </u>	-	-		-
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	l .			1.				
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			1.					
parasitic diseases)	*	-	*	-	-	-	-	-
J (Diseases of the	*	*	*					
respiratory system)	T I	T	T	-	-	-	-	-
R (Symptoms, signs and abnormal clinical and								
laboratory findings, not								
elsewhere classified)	*	_	*	_	_	_	<u> </u>	_
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)	*	-	-	*	-	-	-	-			
1210/4											
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)	*	-	*	~	-	-	-	<del>-</del>		
K81.0 (Acute cholecystitis) K92.9 (Disease of digestive		-		-	-	-	-	<u>-</u>		
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			l.								
system)	6 (20.7%)	-	*	*	-	-	-	-			
M (Diseases of the											
musculoskeletal system and	<u>.</u>										
connective tissue)	*	*	-	-	-	-	-	-			
N (Diseases of the	*										
genitourinary system)	1	-	-	1	-	<u> </u> -	-	-			

			Never 7	Freated   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	C	0	C		*	*	0
Osteoporosis	0	C	0	C		*	*	0
Pulmonary infections	0	C	0	C		) *	*	0
Sleep apnea	0	C	0	C		) *	*	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 T	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)
Score for Belgium ACTIVLIM PRO at genetic report date								
Mean (SD)	-4.9 (4.4)	*	-7.7 (0.9)	-4.5 (3.9)	*	-	-	*
Median [IQR]	-8.1 [-8.1, -2.9]	*	-8.1 [-8.1, -8.1]	-5.2 [-8.1, -2.7]	*	-	-	*
Missing	800 (94.5%)	153 (99.4%)	344 (95.3%)	275 (92.0%)	10 (76.9%)	*	*	14 (87.5%)
Best score for Belgium ACTIVLIM PRO								
Mean (SD)	-4.6 (4.5)	*	-7.7 (0.9)	-3.9 (3.9)	*	-	-	*
Median [IQR]	-6.6 [-8.1, -2.7]	*	-8.1 [-8.1, -8.1]	-3.5 [-8.1, -2.6]	*	-	-	*
Missing	801 (94.6%)	153 (99.4%)	344 (95.3%)	276 (92.3%)	10 (76.9%)	*	*	14 (87.5%)
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								
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	-	-	-	-	-	-	-	-			
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)	-	-	-	-			

	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]	-8.1 [-8.1, -5.6]	-	*	-6.6 [-8.1, -4.1]	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
51 - 61 years										
Mean (SD)	-5.8 (2.4)	-	-	-5.8 (2.4)	-	-	-	-		
Median [IQR]	-6.5 [-8.1, -3.5]	-	-	-6.5 [-8.1, -3.5]	-	-	-	-		
Missing	-	-	-	-	-	-	-	-		
> 60 years										
Mean (SD)	*	-	-	-	*	-	-	-		
Median [IQR]	*	-	-	-	*	-	-	-		
Missing	-	-	_	_	_	_	-	-		

			Trea	ated   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%)

			Trea	nted   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%)	-	-	-	-

			Trea	nted   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%)	-	*	*	*

			Trea	nted   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%)	*	-	-	*

			Trea	ited   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]	-	*	-	*

			Trea	nted   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)	*	-	-	-

			Trea	nted   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)	-	*	-	*

			Trea	ated   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]	*	-	-	-

			Trea	nted   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	29 (37.2%)	-	*	26 (42.6%)	-	-	-	-
> 60 years								
Mean (SD)	80.1 (23.4)	-	-	80.8 (23.9)	*	-	-	-
Median [IQR]	79 [62, 90]	-	-	79.5 [61.8, 93.8]	*	-	-	-
Missing	14 (45.2%)	-	-	13 (44.8%)	*	-	-	-
Age at first acquisition of the best motor ability								
Mean (SD)	18.6 (18.1)	3.3 (4.2)	15.4 (13.5)	29 (19.5)	46.9 (12)	*	*	2.2 (1.1)
Median [IQR]	12.2 [3.8, 28.7]	2.2 [1.3, 3.6]	11.5 [4.8, 20.2]	24.2 [12.2, 46.2]	45 [37.8, 59.2]	*	*	1.8 [1.3, 3.3]
Missing	321 (24.3%)	94 (34.1%)	135 (25.0%)	85 (17.9%)	-	-	*	*
Age at first loss of the best motor ability episodes								
Mean (SD)	27.9 (19)	10.3 (9.6)	21.8 (14.6)	38.8 (19.5)	*	-	-	-
Median [IQR]	21.3 [12.6, 44.2]	6.8 [2.6, 12.5]	17.3 [11.5, 32.6]	41.6 [20.2, 56.4]	*	-	-	-
Missing	903 (68.4%)	250 (90.6%)	314 (58.1%)	312 (65.5%)	7 (77.8%)	*	7 (100.0%)	9 (100.0%)
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	21 (100.0%)	19 (100.0%)	*	-	-	-	-	*
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	64 (86.5%)	51 (86.4%)	12 (85.7%)	-	-	-	-	*
Yes	10 (13.5%)	8 (13.6%)	*	-	-	-	-	-
1.5 - 2 years								

			Trea	nted   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%)	*	-	-	-

			Trea	nted   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%)	*	-	-	-	-	-

			Trea	ated   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)
2 - 6 years								
>1	72 (18.5%)	48 (27.7%)	22 (13.7%)	*	-	-	-	-
0	286 (73.5%)	112 (64.7%)	126 (78.3%)	44 (86.3%)	-	*	-	*
1	31 (8.0%)	13 (7.5%)	13 (8.1%)	5 (9.8%)	-	-	-	-
6 - 11 years								
>1	97 (34.2%)	26 (46.4%)	55 (35.7%)	16 (21.6%)	-	-	-	-
0	156 (54.9%)	27 (48.2%)	80 (51.9%)	49 (66.2%)	-	-	-	-
1	31 (10.9%)	*	19 (12.3%)	9 (12.2%)	-	-	-	-
11 - 16 years								
>1	88 (38.1%)	7 (35.0%)	60 (48.4%)	20 (23.3%)	-	-	-	*
0	116 (50.2%)	13 (65.0%)	55 (44.4%)	48 (55.8%)	-	-	-	-
1	27 (11.7%)	-	9 (7.3%)	18 (20.9%)	-	-	-	-
16 - 21 years								
>1	70 (38.3%)	6 (40.0%)	42 (43.3%)	22 (31.4%)	-	-	-	-
0	104 (56.8%)	9 (60.0%)	51 (52.6%)	43 (61.4%)	-	-	-	*
1	9 (4.9%)	-	*	5 (7.1%)	-	-	-	-
21 - 31 years								
>1	46 (28.7%)	7 (63.6%)	30 (44.8%)	9 (11.2%)	-	-	-	-
0	101 (63.1%)	*	34 (50.7%)	61 (76.2%)	*	-	-	*
1	13 (8.1%)	-	*	10 (12.5%)	-	-	-	-
31 - 41 years								
>1	34 (30.6%)	-	26 (55.3%)	8 (13.3%)	-	-	-	-
0	71 (64.0%)	*	19 (40.4%)	48 (80.0%)	*	-	-	-
1	6 (5.4%)	-	*	*	-	-	-	-
41 - 51 years								
>1	26 (23.9%)	-	16 (45.7%)	10 (14.1%)	-	-	-	-
0	76 (69.7%)	-	18 (51.4%)	55 (77.5%)	*	-	-	-
1	7 (6.4%)	-	*	6 (8.5%)	-	-	-	-
51 - 61 years								

			Trea	ated   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	28 (35.9%)	-	15 (93.8%)	13 (21.3%)	-	-	-	-
0	46 (59.0%)	-	-	45 (73.8%)	*	-	-	-
1	*	-	*	*	-	-	-	-
> 60 years								
>1	5 (16.1%)	-	-	5 (17.2%)	-	-	-	-
0	23 (74.2%)	-	-	21 (72.4%)	*	-	-	-
1	*	-	-	*	-	-	-	-
Closest score for CHOP-INTEND								
Mean (SD)	33.8 (16)	27.4 (13.5)	38.8 (14.6)	37.3 (22)	-	*	44.2 (11.5)	38.5 (18.9)
Median [IQR]	33 [23, 44]	25.5 [20, 35.8]	37 [31, 50]	39 [23, 59]	-	*	42.5 [37.2, 50]	43 [28.5, 54.5]
Missing	1092 (82.7%)	170 (61.6%)	449 (83.1%)	459 (96.4%)	9 (100.0%)	*	*	*
Best score for CHOP-INTEND								
Mean (SD)	44 (15.2)	42.4 (14.9)	44.6 (14.5)	45.5 (18.6)	-	*	49.3 (14.1)	*
Median [IQR]	46 [33.8, 56.2]	44 [33, 54]	46 [35, 57.5]	51 [28.5, 64]	-	*	53 [38, 62]	*
Missing	1105 (83.6%)	170 (61.6%)	453 (83.9%)	466 (97.9%)	9 (100.0%)	*	*	5 (55.6%)
Most recent score for CHOP-INTEND								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-

	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]	-	*	*	-	-	-	*			

			Trea	ted   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	-	-	-	-	-	-	-	-
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 HFMS(- E)								
Mean (SD)	25.4 (20.9)	13.7 (17.9)	13.8 (13.4)	38.5 (19.1)	40.8 (13.6)	*	*	38 (21.4)
Median [IQR]	22 [5, 44]	6 [1, 18.2]	10 [2, 23]	43 [24, 54]	36 [33, 56]	*	*	42 [33, 53]
Missing	905 (68.5%)	220 (79.7%)	375 (69.4%)	293 (61.6%)	*	*	6 (85.7%)	*
Best score for HFMS(-E)								
Mean (SD)	29.7 (21.6)	18.3 (17.8)	18 (16.1)	43.1 (18.6)	45.4 (16.8)	*	*	*
Median [IQR]	29 [8.2, 50]	15 [3, 27]	12.5 [4, 31.2]	50 [29.8, 58]	44 [39, 62]	*	*	*
Missing	907 (68.7%)	221 (80.1%)	372 (68.9%)	296 (62.2%)	*	*	6 (85.7%)	5 (55.6%)
Most recent score for HFMS(-E)								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-

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]	-	-	*			

			Trea	nted   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)	-	-	-	-

			Trea	nted   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]	*	-	-	-

			Trea	nted   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	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for HINE-2								
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%)
Best score for HINE-2								
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%)
Most recent score for HINE-2								
< 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)	-	-	-	-	-	-	-	-

	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	-	-	-	-	-	-	-	-			
1.5 - 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]	-	-	-	-	-	-	-	-			

			Trea	nted   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	-	-	-	-	-	-	-	-
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 MFM32								
Mean (SD)	46.7 (24.7)	*	34 (13.6)	66.4 (23)	-	-	-	-
Median [IQR]	42.5 [27.8, 66.2]	*	36 [26, 43]	71 [47.5, 86]	-	-	-	-
Missing	1237 (93.6%)	272 (98.6%)	495 (91.7%)	441 (92.6%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Best score for MFM32								
Mean (SD)	51.2 (25.6)	*	37.3 (14.6)	73 (21.4)	-	-	-	-
Median [IQR]	48 [31.5, 75]	*	37 [26, 48]	80 [53.5, 90]	-	-	-	-
Missing	1246 (94.3%)	273 (98.9%)	499 (92.4%)	445 (93.5%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Most recent score for MFM32								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-

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]	-	-	-	-		

			Trea	ated   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)	
Missing	-	-	-	-	-	-	-	-	
Change between scores in HFSM-E in consecutive age classes									
< 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)	-	-	-	-	-	-	-	-	

			Trea	ted   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	-	-	-	-	-	-	-	-
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								

	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	-	-	-	-	-	-	-	-		
Change between scores in RULM in consecutive age classes										
< 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	-	-	-	-	-	-	-	-		

	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)			
Missing	-	-	-	-	-	-	-	-			
> 60 years											
Mean (SD)	-	-	-	-	-	-	-	-			
Median [IQR]	-	-	-	-	-	-	-	-			
Missing	-	-	-	-	-	-	-	-			
Change between scores in 6MWT in consecutive age classes											
< 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)	-	-	-	-	-	-	-	-			

	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	-	-	-	-	-	-	-	-			
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											

			Trea	nted   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]	-	-	-	-

			Trea	nted   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	1236 (93.6%)	272 (98.6%)	494 (91.5%)	441 (92.6%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Age at report of (first) 6MWT best score								
Mean (SD)	22.6 (15.4)	-	*	21.5 (15)	42.5 (9.9)	-	-	*
Median [IQR]	17.8 [10.4, 30.6]	-	*	16 [10.1, 28.8]	41.3 [38.8, 45.8]	-	-	*
Missing	1206 (91.3%)	276 (100.0%)	539 (99.8%)	369 (77.5%)	*	*	7 (100.0%)	8 (88.9%)
Ever diagnosed with scoliosis; n (%)								
< 1 month								
No	*	-	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	*	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	25 (64.1%)	18 (60.0%)	*	-	-	*	*	*
Yes	14 (35.9%)	12 (40.0%)	*	-	-	-	-	-
1.5 - 2 years								
No	15 (65.2%)	9 (64.3%)	*	*	-	-	-	*
Yes	8 (34.8%)	5 (35.7%)	*	-	-	-	-	-
2 - 6 years								
No	107 (49.5%)	41 (36.3%)	41 (54.7%)	21 (87.5%)	-	*	-	*
Yes	109 (50.5%)	72 (63.7%)	34 (45.3%)	*	-	-	-	-
6 - 11 years								

			Trea	nted   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	56 (29.8%)	9 (23.1%)	25 (23.6%)	22 (51.2%)				
Yes	132 (70.2%)	30 (76.9%)	81 (76.4%)	21 (48.8%)	-	-	-	-
11 - 16 years	132 (70.270)	30 (70.570)	81 (70.470)	21 (40.070)		-	-	-
No	18 (12.0%)	-	*	16 (29.6%)	_	_	_	_
Yes	132 (88.0%)	13 (100.0%)	81 (97.6%)	38 (70.4%)	-	-	-	-
16 - 21 years								
No	9 (7.5%)	-	-	9 (23.1%)	-	-	-	-
Yes	111 (92.5%)	6 (100.0%)	75 (100.0%)	30 (76.9%)	-	-	-	-
21 - 31 years								
No	31 (24.4%)	*	*	28 (43.1%)	*	-	-	-
Yes	96 (75.6%)	9 (90.0%)	50 (98.0%)	37 (56.9%)	-	_	_	_
31 - 41 years								
No	22 (23.9%)	*	-	20 (44.4%)	*	-	-	-
Yes	70 (76.1%)	*	43 (100.0%)	25 (55.6%)	*	-	-	-
41 - 51 years								
No	32 (37.6%)	-	-	30 (54.5%)	*	-	-	-
Yes	53 (62.4%)	-	27 (100.0%)	25 (45.5%)	*	-	-	-
51 - 61 years								
No	33 (47.8%)	-	*	32 (61.5%)	-	-	-	-
Yes	36 (52.2%)	-	15 (93.8%)	20 (38.5%)	*	-	-	-
> 60 years								
No	22 (73.3%)	-	-	21 (72.4%)	*	-	-	-
Yes	8 (26.7%)	-	-	8 (27.6%)	-	-	-	-
Cobb angle value; n (%)								
< 1 month								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-

			Trea	nted   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%)	-	-	-	-

			Trea	nted   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)
>45°	21 (36.2%)	6 (46.2%)	13 (35.1%)	*	-	-	-	-
30-45°	9 (15.5%)	*	8 (21.6%)	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
<30°	11 (18.6%)	*	*	5 (23.8%)	-	-	-	*
>45°	40 (67.8%)	*	25 (75.8%)	13 (61.9%)	-	-	-	-
30-45°	8 (13.6%)	*	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
<30°	11 (39.3%)	*	*	7 (46.7%)	-	-	-	-
>45°	14 (50.0%)	*	6 (54.5%)	7 (46.7%)	-	-	-	-
30-45°	*	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
<30°	7 (58.3%)	-	*	6 (75.0%)	-	-	-	-
>45°	5 (41.7%)	-	*	*	*	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
<30°	7 (63.6%)	-	*	5 (83.3%)	*	-	-	-
>45°	*	-	*	*	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
<30°	*	-	*	-	-	*	-	-
>45°	-	-	-	-	-		-	-
30-45°	-	-	-	-	-		-	-
Missing	-	-	-	-	-		-	-
51 - 61 years								

			Trea	nted   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%)	*	*	-	-	-	-

			Trea	ated   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	-	-	-	-	-	-	-	-
2 - 6 years								
No	155 (97.5%)	96 (97.0%)	48 (98.0%)	11 (100.0%)	-	-	-	-
Yes	*	*	*	-	-	-	-	-
6 - 11 years								
No	145 (79.2%)	39 (81.2%)	82 (75.2%)	24 (92.3%)	-	-	-	-
Yes	38 (20.8%)	9 (18.8%)	27 (24.8%)	*	-	-	-	-
11 - 16 years								
No	52 (34.7%)	5 (38.5%)	17 (18.5%)	30 (66.7%)	-	-	-	-
Yes	98 (65.3%)	8 (61.5%)	75 (81.5%)	15 (33.3%)	-	-	-	-
16 - 21 years								
No	41 (32.8%)	5 (55.6%)	5 (6.6%)	31 (77.5%)	-	-	-	-
Yes	84 (67.2%)	*	71 (93.4%)	9 (22.5%)	-	-	-	-
21 - 31 years								
No	58 (48.3%)	8 (72.7%)	8 (16.0%)	42 (71.2%)	-	-	-	-
Yes	62 (51.7%)	*	42 (84.0%)	17 (28.8%)	-	-	-	-
31 - 41 years								
No	62 (66.7%)	*	21 (46.7%)	38 (84.4%)	*	-	-	-
Yes	31 (33.3%)	-	24 (53.3%)	7 (15.6%)	-	-	-	-
41 - 51 years								
No	59 (74.7%)	*	14 (50.0%)	43 (87.8%)	*	-	-	-
Yes	20 (25.3%)	-	14 (50.0%)	6 (12.2%)	-	-	-	-
51 - 61 years								
No	58 (86.6%)	-	12 (75.0%)	45 (90.0%)	*	-	-	-
Yes	9 (13.4%)	-	*	5 (10.0%)	-	-	-	-
> 60 years								
No	30 (100.0%)	-	-	29 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-

			Trea	nted   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 surgery for scoliosis								
Mean (SD)	21.3 (17.6)	7 (7.2)	18.7 (13.3)	32.9 (18.7)	48.5 (12.2)	*	*	2.8 (1.1)
Median [IQR]	15.4 [7.2, 31.8]	4.8 [2.7, 7.8]	14.6 [8.7, 25.1]	29.6 [16.8, 48.9]	46 [40.3, 60.6]	*	*	3.3 [1.8, 3.6]
Missing	208 (15.7%)	47 (17.0%)	63 (11.7%)	86 (18.1%)	*	*	6 (85.7%)	*
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	1321 (100.0%)	276 (100.0%)	540 (100.0%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Forced vital capacity percent								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-

	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]	-	-	-	-		

			Trea	nted   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	10 (12.3%)	-	6 (14.6%)	*	-	-	-	-
21 - 31 years								
Mean (SD)	64.4 (33.5)	*	38.3 (21.6)	86.8 (21.3)	*	-	-	*
Median [IQR]	64 [37, 93]	*	36 [20, 57.5]	90 [70, 101]	*	-	-	*
Missing	7 (10.6%)	-	*	*	-	-	-	-
31 - 41 years								
Mean (SD)	68.8 (38.9)	*	44.7 (38.2)	91.7 (20.9)	*	-	-	-
Median [IQR]	80 [33.8, 94]	*	33.5 [20.2, 58.8]	92 [83, 105]	*	-	-	-
Missing	7 (12.7%)	*	5 (18.5%)	*	-	-	-	-
41 - 51 years								
Mean (SD)	84.4 (28.2)	-	48.8 (22.5)	95.2 (19.5)	*	-	-	-
Median [IQR]	89 [72, 105]	-	46.5 [33.4, 57.8]	92 [85.5, 108]	*	-	-	-
Missing	*	-	-	*	-	-	-	-
51 - 61 years								
Mean (SD)	82.6 (34.4)	-	34.4 (20.1)	95.9 (24.1)	-	-	-	-
Median [IQR]	89 [66, 104.5]	-	29 [20, 46]	93 [74, 107.5]	-	-	-	-
Missing	5 (17.9%)	-	*	*	-	-	-	-
> 60 years								
Mean (SD)	88.3 (30.2)	-	-	88.1 (31.5)	*	-	-	-
Median [IQR]	92 [71.8, 101]	-	-	93 [70.5, 104]	*	-	-	-
Missing	*	-	-	-	*	-	-	-
Forced vital capacity volume								
< 1 month								

			Trea	ted   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	-	-	-	-	-	-	-	-
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)	0.9 (0.3)	*	1 (0.2)	-	-	-	-	-
Median [IQR]	0.9 [0.8, 1]	*	0.9 [0.8, 1.2]	-	-	-	-	-
Missing	16 (66.7%)	5 (62.5%)	9 (64.3%)	*	-	-	-	-
6 - 11 years								
Mean (SD)	1.3 (0.7)	0.6 (0.4)	1 (0.5)	1.9 (0.4)	-	-	-	-
Median [IQR]	1.4 [0.8, 1.9]	0.4 [0.4, 0.7]	0.9 [0.7, 1.4]	1.9 [1.7, 2.1]	-	-	-	-
Missing	30 (33.3%)	5 (33.3%)	21 (43.8%)	*	-	-	-	-
11 - 16 years								

			Trea	nted   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)	1.9 (1.2)	*	1.1 (0.7)	2.7 (0.9)	-	-	-	*
Median [IQR]	2 [0.9, 2.6]	*	0.9 [0.5, 1.6]	2.5 [2.2, 3.4]	-	-	-	*
Missing	24 (25.0%)	-	16 (32.7%)	8 (18.2%)	-	-	-	-
16 - 21 years								
Mean (SD)	2.3 (1.5)	*	1.4 (0.8)	3.3 (1.3)	-	-	-	-
Median [IQR]	1.8 [1.1, 3.4]	*	1.2 [0.8, 1.5]	3.4 [2.2, 4.1]	-	-	-	-
Missing	25 (30.9%)	*	15 (36.6%)	9 (25.0%)	-	-	-	-
21 - 31 years								
Mean (SD)	2.9 (1.7)	*	1.7 (1.2)	3.9 (1.1)	*	-	-	*
Median [IQR]	2.7 [1.5, 4]	*	1.4 [0.9, 2.1]	3.9 [3.2, 4.9]	*	-	-	*
Missing	14 (21.2%)	*	5 (18.5%)	8 (22.9%)	-	-	-	-
31 - 41 years								
Mean (SD)	2.6 (1.6)	*	1.4 (1.1)	3.9 (1)	*	-	-	-
Median [IQR]	2.6 [0.9, 4.1]	*	1 [0.7, 1.9]	4.1 [3.6, 4.7]	*	-	-	-
Missing	15 (27.3%)	*	7 (25.9%)	7 (29.2%)	-	-	-	-
41 - 51 years								
Mean (SD)	3.9 (1.3)	-	*	4.1 (1.2)	*	-	-	-
Median [IQR]	3.7 [3.2, 5]	-	*	3.7 [3.4, 5.1]	*	-	-	-
Missing	19 (42.2%)	-	6 (60.0%)	13 (39.4%)	-	-	-	-
51 - 61 years								
Mean (SD)	2.9 (1.5)	-	*	3.6 (1.1)	-	-	-	-
Median [IQR]	3.2 [1.8, 3.9]	-	*	3.7 [3, 4.2]	-	-	-	-
Missing	11 (39.3%)	-	*	9 (40.9%)	-	-	-	-
> 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 (%)								

			Trea	nted   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%)	*	-	-	-	-	-		

			Trea	ated   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	74 (83.1%)	73 (84.9%)	-	-	-	-	-	*
2 - 6 years								
No	10 (8.3%)	8 (8.0%)	*	-	-	-	-	-
Yes	111 (91.7%)	92 (92.0%)	18 (90.0%)	-	-	-	-	*
6 - 11 years								
No	*	*	*	*	-	-	-	-
Yes	75 (94.9%)	29 (93.5%)	45 (97.8%)	*	-	-	-	-
11 - 16 years								
No	*	*	-	-	-	-	-	-
Yes	78 (98.7%)	10 (90.9%)	66 (100.0%)	*	-	-	-	-
16 - 21 years								
No	*	-	*	-	-	-	-	-
Yes	51 (96.2%)	9 (100.0%)	42 (95.5%)	-	-	-	-	-
21 - 31 years								
No	*	-	*	-	-	-	-	-
Yes	35 (97.2%)	9 (100.0%)	25 (96.2%)	*	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	19 (100.0%)	-	18 (100.0%)	*	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	16 (100.0%)	-	9 (100.0%)	7 (100.0%)	-	-	-	-
51 - 61 years								
No	*	-	-	*	-	-	-	-
Yes	17 (94.4%)	-	8 (100.0%)	9 (90.0%)	-	-	-	-
> 60 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	*	-	-	*	-	-	-	-		
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%)	-	-	-	-	-		

			Trea	ted   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)	
Yes	-	-	-	-	-	-	-	-	
6 - 18 months									
No	85 (98.8%)	83 (98.8%)	*	-	-	-	-	*	
Yes	*	*	-	-	-	-	-	-	
1.5 - 2 years									
No	88 (98.9%)	85 (98.8%)	*	-	-	-	-	*	
Yes	*	*	-	-	-	-	-	-	
2 - 6 years									
No	120 (99.2%)	99 (99.0%)	20 (100.0%)	-	-	-	-	*	
Yes	*	*	-	-	-	-	-	-	
6 - 11 years									
No	78 (98.7%)	31 (100.0%)	45 (97.8%)	*	-	-	-	-	
Yes	*	-	*	-	-	-	-	-	
11 - 16 years									
No	78 (98.7%)	11 (100.0%)	65 (98.5%)	*	-	-	-	-	
Yes	*	-	*	-	-	-	-	-	
16 - 21 years									
No	52 (98.1%)	9 (100.0%)	43 (97.7%)	-	-	-	-	-	
Yes	*	-	*	-	-	-	-	-	
21 - 31 years									
No	35 (97.2%)	9 (100.0%)	25 (96.2%)	*	-	-	-	-	
Yes	*	-	*	-	-	-	-	-	
31 - 41 years									
No	18 (94.7%)	-	17 (94.4%)	*	-	-	-	-	
Yes	*	-	*	-	-	-	-	-	
41 - 51 years									
No	16 (100.0%)	-	9 (100.0%)	7 (100.0%)	-	-	-	-	
Yes	-	-	-	-	-	-	-	-	
51 - 61 years									

			Trea	ated   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%)	*	-	-	-	-

			Trea	nted   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	10 (12.7%)	8 (25.8%)	*	-	-	-	-	-
11 - 16 years								
No	72 (91.1%)	9 (81.8%)	61 (92.4%)	*	-	-	-	-
Yes	7 (8.9%)	*	5 (7.6%)	-	-	-	-	-
16 - 21 years								
No	49 (92.5%)	6 (66.7%)	43 (97.7%)	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	30 (83.3%)	5 (55.6%)	24 (92.3%)	*	-	-	-	-
Yes	6 (16.7%)	*	*	-	-	-	-	-
31 - 41 years								
No	14 (73.7%)	-	13 (72.2%)	*	-	-	-	-
Yes	5 (26.3%)	-	5 (27.8%)	-	-	-	-	-
41 - 51 years								
No	13 (81.2%)	-	7 (77.8%)	6 (85.7%)	-	-	-	-
Yes	*	-	*	*	-	-	-	-
51 - 61 years								
No	10 (55.6%)	-	*	7 (70.0%)	-	-	-	-
Yes	8 (44.4%)	-	5 (62.5%)	*	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full- time non-invasive ventilation episode (years)								
Mean (SD)	5.1 (7.8)	1.2 (1.2)	*	-	-	-	-	-
Median [IQR]	2 [0.5, 4]	0.7 [0.5, 2]	*	-	-	-	-	-
Missing	1308 (99.0%)	267 (96.7%)	536 (99.3%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
At least one episode of any invasive ventilation; n (%)								

	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	*	*	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
3 - 6 months											
No	6 (75.0%)	6 (75.0%)	-	-	-	-	-	-			
Yes	*	*	-	-	-	-	-	-			
6 - 18 months											
No	*	*	-	-	-	-	-	-			
Yes	13 (81.2%)	13 (81.2%)	-	-	-	-	-	-			
1.5 - 2 years											
No	5 (26.3%)	5 (26.3%)	-	-	-	-	-	-			
Yes	14 (73.7%)	14 (73.7%)	-	-	-	-	-	-			
2 - 6 years											
No	*	*	-	-	-	-	-	-			
Yes	35 (97.2%)	35 (97.2%)	-	-	-	-	-	-			
6 - 11 years											
No	*	*	-	-	-	-	-	-			
Yes	20 (90.9%)	18 (90.0%)	*	-	-	-	-	-			
11 - 16 years											
No	-	-	-	-	-	-	-	-			
Yes	12 (100.0%)	9 (100.0%)	*	-	-	-	-	-			
16 - 21 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	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	-	-	-	-	-	-	-	-			
> 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	8 (100.0%)	8 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
6 - 18 months											
No	16 (100.0%)	16 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
1.5 - 2 years											
No	19 (100.0%)	19 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
2 - 6 years											
No	34 (94.4%)	34 (94.4%)	-	-	-	-	-	-			
Yes	*	*	-	-	-	-	-	-			
6 - 11 years											
No	21 (95.5%)	19 (95.0%)	*	-	-	-	-	-			
Yes	*	*	-	-	-	-	-	-			
11 - 16 years											

	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	12 (100.0%)	9 (100.0%)	*	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
16 - 21 years											
No	7 (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	-	-	-	-	-	-	-	-			
At least one episode of part-time sleeping invasive ventilation; n (%)											
< 1 month											
No	-	-	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
1 - 3 months											

	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	*	*	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
3 - 6 months											
No	8 (100.0%)	8 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
6 - 18 months											
No	16 (100.0%)	16 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
1.5 - 2 years											
No	19 (100.0%)	19 (100.0%)	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
2 - 6 years											
No	34 (94.4%)	34 (94.4%)	-	-	-	-	-	-			
Yes	*	*	-	-	-	-	-	-			
6 - 11 years											
No	20 (90.9%)	19 (95.0%)	*	-	-	-	-	-			
Yes	*	*	*	-	-	-	-	-			
11 - 16 years											
No	12 (100.0%)	9 (100.0%)	*	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
16 - 21 years											
No	7 (100.0%)	*	*	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
21 - 31 years											
No	*	*	*	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
31 - 41 years											
No	-	-	-	-	-	-	-	-			

			Trea	nted   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%)	*	-	*	-	*

			Trea	nted   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)			
Yes	44 (86.3%)	*	34 (87.2%)	6 (100.0%)	-	-	-	-			
16 - 21 years											
No	*	-	*	-	-	-	-	-			
Yes	28 (96.6%)	5 (100.0%)	22 (95.7%)	*	-	-	-	-			
21 - 31 years											
No	-	-	-	-	-	-	-	-			
Yes	18 (100.0%)	5 (100.0%)	12 (100.0%)	*	-	-	-	-			
31 - 41 years											
No	*	-	-	*	-	-	-	-			
Yes	10 (90.9%)	-	9 (100.0%)	*	-	-	-	-			
41 - 51 years											
No	-	-	-	-	-	-	-	-			
Yes	10 (100.0%)	-	6 (100.0%)	*	-	-	-	-			
51 - 61 years											
No	*	-	-	*	-	-	-	-			
Yes	9 (90.0%)	-	*	6 (85.7%)	-	-	-	-			
> 60 years											
No	*	-	-	*	-	-	-	-			
Yes	*	-	-	*	-	-	-	-			
At least one episode of feeding tube usage; n (%)											
< 1 month											
No	-	-	-	-	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
1 - 3 months											
No	9 (64.3%)	9 (64.3%)	-	-	-	-	-	-			
Yes	5 (35.7%)	5 (35.7%)	-	-	-	-	-	-			
3 - 6 months											

	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)			
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	10 (100.0%)	7 (100.0%)	-	-	-	-	*	-			
Yes	-	-	-	-	-	-	-	-			
3 - 6 months											
No	21 (100.0%)	17 (100.0%)	-	*	-	-	*	-			
Yes	-	-	-	-	-	-	-	-			
6 - 18 months											
No	69 (100.0%)	54 (100.0%)	12 (100.0%)	*	-	*	-	*			
Yes	-	-	-	-	-	-	-	-			
1.5 - 2 years											
No	49 (100.0%)	30 (100.0%)	17 (100.0%)	*	-	-	-	-			
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)			
2 - 6 years											
No	171 (100.0%)	88 (100.0%)	64 (100.0%)	18 (100.0%)	-	-	-	*			
Yes	-	-	-	-	-	-	-	-			
6 - 11 years											
No	129 (100.0%)	29 (100.0%)	71 (100.0%)	29 (100.0%)	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
11 - 16 years											
No	100 (100.0%)	7 (100.0%)	55 (100.0%)	38 (100.0%)	-	-	-	-			
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	38 (100.0%)	*	19 (100.0%)	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%)	-	-	-	-			
Yes	-	-	-	-	-	-	-	-			
> 60 years											
No	13 (100.0%)	-	-	11 (100.0%)	*	-	-	-			
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%)	-	-	-	-		

			Trea	nted   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 (%)							(2.4		
A49.9 (Bacterial									
infection, unspecified)	-	-	-	-	-	-	-	-	
J18 (Pneumonia, organism	<b>.</b>	*							
unspecified)	*	*	-	-	-	-	-	-	
J22 (Unspecified acute									
lower respiratory infection)	-	-	-	-	-	-	-	-	
J96.0 (Acute respiratory	_	_	_	<sub>-</sub>	_	<sub>-</sub>	_	_	
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	_	_	_	<sub>-</sub>	_	<sub>-</sub>	_	_	
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)			
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	1318 (99.8%)	274 (99.3%)	539 (99.8%)	476 (100.0%)	9 (100.0%)	*	7 (100.0%)	9 (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)	-	-	-	-	-	-	-	-			

	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)		
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 mellitusith 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)	-	-	-	-	-	-	-	-		

	Treated   SMA Type										
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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)	<b>_</b>	-	Î	-	-	-	-	-			
J06.9 (Acute upper											
respiratory infection,	10 (6.0%)	7 (10.4%)	*	-	-	-	-	-			
unspecified)											
J09 (Influenza due to	*	*									
identified zoonotic or pandemic influenza virus)	<b> </b> *	*	-	-	-	-	-	-			
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)			l	I							

	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										
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)			
J96.9 (Respiratory failure, unspecified)	*	*	-	-	-	-	-	-			
J98.1 (Pulmonary collapse)	-	-	-	-	-	-	-	-			
J98.7 (Respiratory infections, not elsewhere classified)	27 (16.3%)	19 (28.4%)	8 (11.6%)	-	-	-	-	-			
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)	8 (4.8%)	-	*	5 (17.2%)	-	-	-	-			
K94.2 (Gastrostomy complications)	*	*	-	-	-	-	-	-			
M41 (Scoliosis)	*	-	*	-	-	-	-	-			
M41.4 (Neuromuscular scoliosis)	*	-	-	*	-	-	-	-			
M80 (Osteoporosis with pathological fracture)	-	-	-	-	-	-	-	-			

	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)			
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										
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)			
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	*	-	*	-	-	-	-	-			
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)	*	*	-	-	-	-	-	-			

	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)			
E86 (Volume depletion)	*	*	-	-	-	-	-	-			
E87 (Other disorders of fluid, electrolyte and acidbase 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)	-	-	-	-	-	-	-	-			
186 (Varicose veins of other sites)	*	-	*	-	-	-	-	-			
J03 (Acute tonsillitis)	*	-	*	-	-	-	-	-			

	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)			
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)	*	*	-	-	-	-	-	-			
Leicewhere 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										
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)			
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,	*	-	-	-	*	-	-	-			
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										
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)		
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)	10 (6.0%)	*	*	8 (27.6%)	-	-	-	-		
T45 (Poisoning by primarily systemic and haematological agents, not elsewhere classified)	-	-	-	-	-	-	-	-		

			Trea	ted   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)
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)	*	-	*	-	-	-	-	-

			Trea	ted   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)
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

			Trea	ated   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)
Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Mean (SD)	43.6 (25.9)	63 (24.3)	50.4 (19.6)	20.8 (19)	-	-	-	-
Median [IQR]	44 [22.3, 66.1]	65.9 [46.5, 80.6]	51.5 [38.6, 67.8]	13.1 [6, 29.7]	-	-	-	-
Missing	1198 (90.7%)	253 (91.7%)	478 (88.5%)	438 (92.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Best score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	40.8 (26)	62.5 (23.5)	46.3 (19.9)	19.1 (19.6)	-	-	-	-
Median [IQR]	39.5 [17.8, 64.8]	64.5 [48.8, 80.1]	50 [28.2, 66.3]	10.9 [4.8, 27.7]	-	-	-	-
Missing	1207 (91.4%)	254 (92.0%)	484 (89.6%)	440 (92.4%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Most recent score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	43.3 (26.5)	61.3 (26.9)	49.8 (20.1)	21.8 (21.1)	-	-	-	-
Median [IQR]	43.4 [21.2, 65.9]	68.2 [40.7, 82.2]	51.6 [37.5, 66.1]	14.8 [5.4, 29.6]	-	-	-	-
Missing	1198 (90.7%)	253 (91.7%)	478 (88.5%)	438 (92.0%)	9 (100.0%)	*	7 (100.0%)	9 (100.0%)
Score for Belgium ACTIVLIM PRO at genetic report date								
Mean (SD)	-3.4 (4.3)	*	-6.1 (2.3)	-0.7 (3.9)	2.1 (1.6)	-	-	-
Median [IQR]	-3.7 [-8.1, 0.1]	*	-8.1 [-8.1, -3.9]	-0.1 [-3.5, 2.5]	2.8 [2.2, 3.1]	-	-	-
Missing	1173 (88.8%)	272 (98.6%)	470 (87.0%)	407 (85.5%)	*	*	7 (100.0%)	9 (100.0%)
Best score for Belgium ACTIVLIM PRO								
Mean (SD)	-2.9 (4.4)	*	-5.7 (2.5)	-0.3 (4)	2.3 (1.4)	-	-	-
Median [IQR]	-3 [-8.1, 0.4]	*	-6.6 [-8.1, -3.7]	0.1 [-2.4, 2.8]	2.5 [2.2, 2.8]	-	-	-
Missing	1182 (89.5%)	272 (98.6%)	475 (88.0%)	411 (86.3%)	*	*	7 (100.0%)	9 (100.0%)
Most recent score for Belgium ACTIVLIM PRO								

			Trea	ated   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								
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]	-	-	-	-

			Trea	ated   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)	-3.9 (4.8)	*	-6.4 (1.9)	0.6 (4.6)	-	-	-	-
Median [IQR]	-5.1 [-8.1, -0.3]	*	-8.1 [-8.1, -4.6]	2.2 [-2.5, 4.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-4.3 (4.4)	-	-6.4 (2.4)	-0.8 (4.8)	-	-	-	-
Median [IQR]	-6.6 [-8.1, -1.7]	-	-8.1 [-8.1, -4.4]	-0.2 [-3.4, 3.1]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-1.7 (3.4)	-	-6.4 (1.5)	-0.1 (2.2)	*	-	-	-
Median [IQR]	-1.1 [-3.9, 1]	-	-5.6 [-8.1, -5.2]	-0.4 [-1.9, 2.1]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-4.3 (4.1)	-	-7 (1.4)	-2.7 (4)	*	-	-	-
Median [IQR]	-6.6 [-8.1, -1.5]	-	-8.1 [-8.1, -6.6]	-2.8 [-6.6, -0.4]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	-2.4 (3.8)	-	*	-2.6 (3.4)	*	-	-	-
Median [IQR]	-0.4 [-5.6, 0.3]	-	*	-2.8 [-5.6, 0.2]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-4.6 (3.6)	-	*	-4.2 (3.6)	-	-	-	-
Median [IQR]	-5.7 [-8.1, -0.8]	-	*	-4.9 [-8.1, 0.1]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	*	-	-	-
Median [IQR]	*	-	-	*	*	-	-	-
Missing	-	-	-	-	-	-	-	-

	Evrysdi   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%)			

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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	-	-	-	-	-	-	-	-

Crawl	-	-	-	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
Roll onto side	*	*	*	-	-	-	-	-
Sit without support	6 (1.5%)	-	6 (2.7%)	-	-	-	-	-
Stand with assistance	-	-	-	-	-	-	-	-
Stand without assistance	*	-	*	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	*	-	-	*	-	-	-	-
Walk with assistance	*	-	*	-	-	-	-	-
Walk without assistance	*	-	-	*	-	-	-	-
Missing	391 (97.0%)	63 (98.4%)	217 (96.0%)	99 (98.0%)	*	*	*	7 (100.0%)
Best achieved motor milestone after treatment; n (%)								
Climb stairs	62 (15.4%)	-	*	55 (54.5%)	*	-	-	*
Crawl	35 (8.7%)	*	32 (14.2%)	*	-	-	-	-
Hold head without support	18 (4.5%)	6 (9.4%)	10 (4.4%)	*	-	-	-	-
Roll onto side	21 (5.2%)	13 (20.3%)	7 (3.1%)	-	-	-	*	-
Sit without support	105 (26.1%)	15 (23.4%)	82 (36.3%)	5 (5.0%)	-	*	-	*
Stand with assistance	20 (5.0%)	*	17 (7.5%)	-	-	-	-	-
Stand without assistance	*	-	*	*	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	27 (6.7%)	-	5 (2.2%)	21 (20.8%)	-	*	-	-
Walk with assistance	31 (7.7%)	-	30 (13.3%)	*	-	-	-	-
Walk without assistance	15 (3.7%)	*	6 (2.7%)	7 (6.9%)	-	-	-	*
Missing	66 (16.4%)	25 (39.1%)	31 (13.7%)	7 (6.9%)	-	-	-	*
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)	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]	-	-	-	-

Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	156.9 (12.6)	155.6 (8.1)	156.7 (14.6)	*	-	-	-	-
Median [IQR]	160 [150, 164.5]	153.5 [149.5, 161.2]	160 [150, 164.2]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	156.6 (9.5)	*	154.7 (8.3)	*	-	-	-	-
Median [IQR]	160 [150, 160]	*	160 [151, 160]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	161.3 (16.6)	-	153.4 (14.9)	174.5 (9.5)	-	-	-	-
Median [IQR]	164.5 [150, 173]	-	155 [148.5, 165]	178 [167, 180]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	152.8 (39)	-	*	153.7 (43.5)	*	-	-	-
Median [IQR]	159 [152, 174.8]	-	*	163.5 [152, 177.8]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Weight (kg)								
< 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)	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%)	*	-	-	-	-

31 - 41 years								
Mean (SD)	55.3 (19.3)	*	52.1 (17.6)	*	-	-	-	-
Median [IQR]	60 [41.2, 66.5]	*	60 [40.2, 64.5]	*	-	-	-	-
Missing	17 (48.6%)	-	14 (50.0%)	*	-	-	-	-
41 - 51 years								
Mean (SD)	72.9 (24.3)	-	64.6 (24.8)	88 (14.2)	-	-	-	-
Median [IQR]	80 [63, 90]	-	63 [46.5, 82.5]	90.5 [81, 97.8]	-	-	-	-
Missing	17 (50.0%)	-	13 (54.2%)	*	-	-	-	-
51 - 61 years								
Mean (SD)	78.1 (28.5)	-	77.2 (38.4)	79 (22.3)	*	-	-	-
Median [IQR]	75 [61, 90]	-	65.5 [56.5, 79.8]	82.5 [65, 93.8]	*	-	-	-
Missing	8 (32.0%)	-	*	5 (33.3%)	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	*	-	-	*	-	-	-	-
Age at first acquisition of the best motor ability								
Mean (SD)	24 (18.2)	6.1 (5)	22.9 (14.5)	34.5 (21.1)	*	*	-	*
Median [IQR]	17.4 [11.2, 35.5]	5.3 [3.3, 6.6]	17.6 [13, 32.2]	27.8 [15.8, 54.5]	*	*	-	*
Missing	151 (37.5%)	39 (60.9%)	76 (33.6%)	32 (31.7%)	-	-	*	*
Age at first loss of the best motor ability episodes								
Mean (SD)	30.4 (18.3)	13.4 (10.2)	26.7 (15)	42.1 (19.9)	-	-	-	-
Median [IQR]	25.5 [14.6, 46.8]	10 [4.7, 24.4]	20.8 [14, 38]	47 [20.6, 58.9]	-	-	-	-
Missing	238 (59.1%)	54 (84.4%)	119 (52.7%)	53 (52.5%)	*	*	*	7 (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	*	-	-	-	-	-	-	*
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%)	-	-	-	-

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51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	22 (100.0%)	-	9 (100.0%)	12 (100.0%)	*	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	8 (100.0%)	-	-	8 (100.0%)	-	-	-	-
Age at first full-time or part-time wheelchair usage (months)								
Mean (SD)	8.2 (12.1)	2.6 (1.4)	4.4 (5)	19.4 (17.8)	*	-	-	*
Median [IQR]	3.3 [2, 8]	2.4 [2, 3]	3 [2, 4.9]	10 [7.2, 31]	*	-	-	*
Missing	136 (33.7%)	30 (46.9%)	64 (28.3%)	32 (31.7%)	-	*	*	6 (85.7%)
Number of contractures; n (%)								
< 1 month								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
1 - 3 months								
>1	-	-	-	-	-	-	-	-
0	*	-	-	-	-	*	-	*
1	-	-	-	-	-	-	-	-
3 - 6 months								
>1	-	-	-	-	-	-	-	-
0	5 (100.0%)	*	-	-	-	*	*	*
1	-	-	-	-	-	-	-	-
6 - 18 months								
>1	*	*	-	-	-	-	-	-
0	9 (90.0%)	5 (83.3%)	-	-	-	*	-	*
1	-	-	-	-	-	-	-	-
1.5 - 2 years								

>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	*	-	*	*	-	-	-	-

51 - 61 years								
>1	16 (64.0%)	-	9 (100.0%)	7 (46.7%)	-	-	-	-
0	7 (28.0%)	-	-	6 (40.0%)	*	-	-	-
1	*	-	-	*	-	-	-	-
> 60 years								
>1	*	-	-	*	-	-	-	-
0	*	-	-	*	-	-	-	-
1	*	-	-	*	-	-	-	-
Closest score for CHOP-INTEND								
Mean (SD)	33 (15.3)	27.3 (14.8)	35.8 (15)	*	-	*	*	*
Median [IQR]	32 [23, 41]	24 [19, 38]	34 [31, 40]	*	-	*	*	*
Missing	338 (83.9%)	35 (54.7%)	201 (88.9%)	97 (96.0%)	*	*	-	*
Best score for CHOP-INTEND								
Mean (SD)	37.8 (14.7)	36 (15.8)	35 (10.1)	*	-	*	-	*
Median [IQR]	36 [28.8, 50.2]	38 [24, 46]	34 [30, 40]	*	-	*	-	*
Missing	367 (91.1%)	47 (73.4%)	213 (94.2%)	99 (98.0%)	*	*	*	5 (71.4%)
Most recent score for CHOP-INTEND								
< 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)	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]	*	-	*	-	-	-	-	-

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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 HFMS(- E)								
Mean (SD)	18.7 (20.6)	6.5 (9.6)	8.9 (9.5)	39.9 (21.2)	*	-	-	*
Median [IQR]	9.5 [2, 33]	2.5 [-, 7.8]	5 [2, 14.5]	45 [27.2, 59.8]	*	-	-	*
Missing	271 (67.2%)	38 (59.4%)	163 (72.1%)	63 (62.4%)	-	*	*	*
Best score for HFMS(-E)								
Mean (SD)	20.8 (20.4)	11.7 (13)	12.5 (13.3)	39.5 (21.1)	*	-	-	*
Median [IQR]	15 [3, 34]	5 [0.5, 20.5]	6 [2.8, 21.2]	39 [24.8, 60]	*	-	-	*
Missing	296 (73.4%)	45 (70.3%)	170 (75.2%)	73 (72.3%)	-	*	*	*
Most recent score for HFMS(-E)								
< 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)	19.5 (13.4)	11.8 (6)	27.2 (14.3)	-	-	-	-	-
Median [IQR]	14.5 [10.2, 28]	12 [9, 17]	31 [11, 40]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	29.1 (19.8)	*	18.8 (12.7)	53.6 (13.2)	-	-	-	-
Median [IQR]	23 [16, 41]	*	19 [9, 28]	58 [55, 62]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	21.4 (23.9)	*	6.9 (6.3)	37.6 (24.3)	-	-	-	*
Median [IQR]	7.5 [4, 45.2]	*	6 [4, 7.5]	52 [17.5, 60.5]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	16.8 (18.9)	-	5.8 (5.6)	34.6 (19.3)	-	-	-	-
Median [IQR]	9 [3, 28]	-	4 [2, 8.8]	31 [21.5, 51]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	5 (9.3)	*	6.3 (10.7)	*	-	-	-	-
Median [IQR]	1.5 [-, 5.2]	*	2 [0.5, 4.5]	*	-	-	-	-
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)	19.2 (13.8)	9.6 (11)	14.8 (9.4)	33.3 (12.8)	*	-	-	*
Median [IQR]	17 [9.5, 26]	8.5 [0.8, 11.2]	15 [7, 20.2]	37 [23, 37]	*	-	-	*
Missing	276 (68.5%)	48 (75.0%)	150 (66.4%)	68 (67.3%)	-	*	*	6 (85.7%)
Best score for RULM								
Mean (SD)	18.9 (11.2)	9.6 (8.2)	15.6 (8.5)	30.3 (9)	*	-	-	*
Median [IQR]	19 [10, 26]	10.5 [-, 14.2]	15 [9, 22]	36 [22, 37]	*	-	-	*
Missing	292 (72.5%)	52 (81.2%)	156 (69.0%)	74 (73.3%)	-	*	*	6 (85.7%)
Most recent score for RULM								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-

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16.9 (7.3)	13.7 (3.1)	20.8 (8.7)	-	-	-	-	-
14 [10.5, 22]	14 [11, 14.8]	25 [11, 26]	-	-	-	-	-
-	-	-	-	-	-	-	-
25.4 (10.4)	*	20.7 (8.3)	37.4 (1.9)	-	-	-	-
27 [19, 36]	*	23.5 [19, 27]	37 [36, 37]	-	-	-	-
-	-	-	-	-	-	-	-
20.7 (11.3)	*	14.6 (5.7)	29.4 (8.6)	-	-	-	*
19 [12, 34]	*	14 [10, 19]	34.5 [21.2, 37]	-	-	-	*
-	-	-	-	-	-	-	-
18.2 (10.1)	*	13.6 (6.4)	28.3 (7.3)	-	-	-	-
18 [11.5, 21.8]	*	14.5 [9.5, 18.2]	27 [21, 37]	-	-	-	-
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Mean (SD)	14.3 (9.8)	*	13.6 (7.1)	*	-	-	-	-
Median [IQR]	15 [7.5, 21]	*	14 [8.2, 20.8]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	11.2 (9.8)	*	12.3 (9.6)	-	-	-	-	-
Median [IQR]	12 [6, 13]	*	12 [7.2, 13.5]	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	18.6 (12.7)	-	*	*	-	-	-	-
Median [IQR]	16 [8, 27]	-	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	*	-	*	-	*	-	-	-
Median [IQR]	*	-	*	-	*	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for HINE-2								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	402 (99.8%)	63 (98.4%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Best score for HINE-2								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	403 (100.0%)	64 (100.0%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Most recent score for HINE-2								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-

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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 MFM32								
Mean (SD)	34.2 (15.7)	*	32.9 (12.4)	43.4 (19.4)	-	-	-	-
Median [IQR]	34 [25, 43.2]	*	35 [26, 42]	42 [26, 49]	-	-	-	-
Missing	363 (90.1%)	62 (96.9%)	197 (87.2%)	92 (91.1%)	*	*	*	7 (100.0%)
Best score for MFM32								
Mean (SD)	37.7 (18.2)	*	35.4 (13.6)	51.8 (22.1)	-	-	-	-
Median [IQR]	35.5 [25.8, 48.2]	*	34.5 [26, 45.2]	46 [35.8, 69.5]	-	-	-	-
Missing	367 (91.1%)	62 (96.9%)	200 (88.5%)	93 (92.1%)	*	*	*	7 (100.0%)
Most recent score for MFM32								

< 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]	-	-	-	-

2.4) - 0, 41.8] -		33.4 (9) 33.5 [27.5, 36.2]	*	-	-	-	-
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			*				
0, 41.8]		33.5 [27.5, 36.2]		-	<u>-</u>	-	-
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(149.1) -		*	375.6 (154)	*	-	-	*
5 [260.8, 475] -		*	436 [270.5, 481.5]	*	-	-	*
94.5%)	64 (100.0%)	225 (99.6%)	82 (81.2%)	-	*	*	6 (85.7%)
(141.9) -	-	*	446.2 (117.8)	*	-	-	*
9	(149.1) - (260.8, 475] - 4.5%)		- * - * * * *	- *	- *	- *	* - *

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	-	-	-	-	-	-	-	-

11 - 16 years								
Mean (SD)	464.3 (111.3)	-	-	463 (120.2)	-	-	-	*
Median [IQR]	496 [416, 536]	-	-	511.5 [394, 540.5]	-	-	-	*
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	-	-	-	-	-	-	-	-
Change between scores in HFSM-E in consecutive age classes								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
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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]	*	*	*	*	<del>-</del>   _	_	-  -	_
Missing					-	-	-	-
wiissiiig		<u> </u> -	<u> </u>	<u> </u>	ļ <del>-</del>	_	ļ <del>-</del>	<del>-</del>

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	-	-	-	-	-	-	-	-
Change between scores in RULM in consecutive age classes								
< 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]	T	-	T	T	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years				*				
Mean (SD)	-	-	-	*	-	-	-	-
Median [IQR]	-	-	-	T	-	-	-	-
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	-	-	-	-	-	-	-	-
Change between scores in 6MWT in consecutive age classes								
< 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								
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)	8.3 (10.1)	4.2 (4.3)	12.1 (10.4)	*	-	*	*	*
Median [IQR]	2.8 [1.7, 12.6]	2.5 [1.6, 4.8]	11.5 [2.7, 14.8]	*	-	*	*	*
Missing	335 (83.1%)	32 (50.0%)	201 (88.9%)	97 (96.0%)	*	*	-	*
Age at report of (first) best HFMS(-E) score								
Mean (SD)	12.9 (9.7)	8.9 (8.7)	13.9 (9.1)	13.3 (8)	*	-	-	*
Median [IQR]	11.2 [6.7, 15.5]	5.2 [3.6, 11.3]	13.2 [7.1, 17.1]	11.2 [9.3, 15]	*	-	-	*
Missing	264 (65.5%)	38 (59.4%)	161 (71.2%)	58 (57.4%)	-	*	*	*
Age at report of (first) best RULM right side score								
Mean (SD)	12.3 (8.4)	5.4 (4.9)	14.8 (12.2)	12.8 (3.1)	-	-	-	*
Median [IQR]	12 [6.2, 15.7]	3.3 [2.8, 5]	10.1 [4.4, 19.2]	12.8 [10.6, 14.7]	-	-	-	*
Missing	357 (88.6%)	56 (87.5%)	210 (92.9%)	80 (79.2%)	*	*	*	6 (85.7%)
Age at report of (first) best HINE-2 score								

Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	402 (99.8%)	63 (98.4%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Age at report of (first) best MFM32 score								
Mean (SD)	15.9 (9.8)	*	16.1 (9.7)	16.1 (10.3)	-	-	-	-
Median [IQR]	13.6 [10.9, 16.6]	*	14.2 [11.1, 16.6]	13.1 [11, 15.5]	-	-	-	-
Missing	362 (89.8%)	62 (96.9%)	196 (86.7%)	92 (91.1%)	*	*	*	7 (100.0%)
Age at report of (first) 6MWT best score								
Mean (SD)	13.9 (10.4)	-	*	11.3 (3.3)	*	-	-	*
Median [IQR]	11.6 [9.4, 14.9]	-	*	11.2 [8.8, 12.2]	*	-	-	*
Missing	379 (94.0%)	64 (100.0%)	225 (99.6%)	80 (79.2%)	-	*	*	6 (85.7%)
Ever diagnosed with 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								

	1.	1.					
		+	-	-	-	-	*
21 (72.4%)	14 (77.8%)	6 (85.7%)	*	-	-	-	-
*	*	*	*	-	-	-	-
40 (90.9%)	9 (90.0%)	27 (93.1%)	*	_	_	-	_
*	-	-	*	-	-	-	-
68 (97.1%)	5 (100.0%)	43 (100.0%)	20 (90.9%)	-	-	-	-
-	-	-	-	-	_	-	-
48 (100.0%)	*	38 (100.0%)	7 (100.0%)	-	-	-	-
*	*	*	-	-	-	-	-
42 (95.5%)	9 (90.0%)	26 (96.3%)	7 (100.0%)	-	_	-	-
*	-	-	*	-	-	-	-
30 (90.9%)	*	27 (100.0%)	*	-	-	-	-
*	-	-	*	-	-	-	-
25 (86.2%)	-	20 (100.0%)	5 (55.6%)	-	-	-	-
7 (26.9%)	-	-	7 (46.7%)	-	-	-	-
	-	10 (100.0%)		*	-	-	-
6 (66.7%)	-	-	6 (66.7%)	-	-	-	-
*	-	-	*	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
	40 (90.9%)  *  68 (97.1%)  -  48 (100.0%)  *  42 (95.5%)  *  30 (90.9%)  *  25 (86.2%)  7 (26.9%)  19 (73.1%)  6 (66.7%)	21 (72.4%)	21 (72.4%) 14 (77.8%) 6 (85.7%)  *	21 (72.4%)       14 (77.8%)       6 (85.7%)       *         *       *       *       *         40 (90.9%)       9 (90.0%)       27 (93.1%)       *         68 (97.1%)       5 (100.0%)       43 (100.0%)       20 (90.9%)         -       -       -       -         48 (100.0%)       *       38 (100.0%)       7 (100.0%)         *       *       -       -         42 (95.5%)       9 (90.0%)       26 (96.3%)       7 (100.0%)         *       -       *         30 (90.9%)       *       27 (100.0%)       *         *       -       -       *         25 (86.2%)       -       20 (100.0%)       5 (55.6%)         7 (26.9%)       -       -       7 (46.7%)         19 (73.1%)       -       10 (100.0%)       8 (53.3%)         6 (66.7%)       -       6 (66.7%)	21 (72.4%)	21 (72.4%)	21 (72.4%) 14 (77.8%) 6 (85.7%) *

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%)	-	-	-	-	-

					1			
11 - 16 years								
No	11 (15.9%)	*	5 (10.2%)	*	-	-	-	-
Yes	58 (84.1%)	*	44 (89.8%)	11 (73.3%)	-	-	-	-
16 - 21 years								
No	11 (19.3%)	*	*	7 (70.0%)	-	-	-	-
Yes	46 (80.7%)	*	41 (95.3%)	*	-	-	-	-
21 - 31 years								
No	12 (27.3%)	7 (70.0%)	5 (19.2%)	-	-	-	-	-
Yes	32 (72.7%)	*	21 (80.8%)	8 (100.0%)	-	-	-	-
31 - 41 years								
No	17 (50.0%)	*	11 (40.7%)	5 (83.3%)	-	-	-	-
Yes	17 (50.0%)	-	16 (59.3%)	*	-	-	-	-
41 - 51 years								
No	18 (60.0%)	*	11 (52.4%)	6 (75.0%)	-	-	-	-
Yes	12 (40.0%)	-	10 (47.6%)	*	-	-	-	-
51 - 61 years								
No	22 (81.5%)	-	6 (60.0%)	15 (93.8%)	*	-	-	-
Yes	5 (18.5%)	-	*	*	-	-	-	-
> 60 years								
No	9 (100.0%)	-	-	9 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at surgery for scoliosis								
Mean (SD)	24.7 (17)	12.5 (10.6)	24 (13.7)	36.2 (20.3)	*	*	-	*
Median [IQR]	18.5 [12.7, 36.1]	7.8 [5.1, 19]	18.5 [13.7, 34]	33.6 [16.5, 55.1]	*	*	-	*
Missing	64 (15.9%)	13 (20.3%)	21 (9.3%)	25 (24.8%)	-	*	*	*
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)	-	-	-	0.1 (0.2)	-	-	*	*
Median [IQR]	-	-	-	-	-	-	*	*
Missing								
Age at first reported vertebral fracture								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	403 (100.0%)	64 (100.0%)	226 (100.0%)	101 (100.0%)	*	*	*	7 (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)	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								
Wissing	-	-	-	-	-	-	-	-
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)	-	-	-	-	-	-	-	-

1							1	T 1
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	1.3 (0.7)	*	1.1 (0.5)	*	-	-	-	-
Median [IQR]	1.4 [0.8, 1.6]	*	1.2 [0.8, 1.4]	*	-	-	-	-
Missing	*	-	*	-	-	-	-	-
11 - 16 years								
Mean (SD)	1.8 (1)	-	1.1 (0.6)	2.3 (0.8)	-	-	-	*
Median [IQR]	1.9 [0.9, 2.5]	-	1.1 [0.7, 1.6]	2.5 [2.1, 2.7]	-	-	-	*
Missing	9 (22.5%)	-	8 (33.3%)	*	-	-	-	-
16 - 21 years								
Mean (SD)	2.2 (1.5)	-	1.4 (0.7)	3.4 (1.6)	-	-	-	-
Median [IQR]	1.6 [1.2, 2.8]	-	1.2 [1, 1.5]	2.9 [2.2, 4.5]	-	-	-	-
Missing	8 (30.8%)	*	5 (31.2%)	*	-	-	-	-
21 - 31 years								
Mean (SD)	1.6 (1.4)	*	1.7 (1.4)	*	-	-	-	-
Median [IQR]	1.2 [0.6, 2.3]	*	1.2 [0.7, 2.1]	*	-	-	-	-
Missing	*	*	*	-	-	-	-	-
31 - 41 years								
Mean (SD)	1.6 (1.2)	*	1.7 (1.2)	-	-	-	-	-
Median [IQR]	1 [0.7, 2.4]	*	1.1 [0.8, 2.5]	-	-	-	-	-
Missing	*	-	*	-	-	-	-	-
41 - 51 years								
Mean (SD)	2.9 (0.8)	-	*	*	-	-	-	-
Median [IQR]	3.2 [2.3, 3.6]	-	*	*	-	-	-	-
Missing	6 (46.2%)	-	*	*	-	-	-	-
51 - 61 years								

Mean (SD)	*		*	*	I_	1_	T_	]_
Median [IQR]	*		*	*		<u> </u>		
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%)	-	-	-	-

	I	Ι.	I	Ι.			Ι	
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								
o 10 months								

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	-	-	-	-	-	-	-	-

37		1						
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									
No	Yes	-	-	-	-	-	-	-	-
Yes	2 - 6 years								
Color	No	14 (100.0%)	12 (100.0%)	*	-	-	-	-	*
No	Yes	-	-	-	-	-	-	-	-
Yes	6 - 11 years								
11 - 16 years	No	14 (93.3%)	*	9 (90.0%)	*	-	-	-	-
No	Yes	*	-	*	-	-	-	-	-
Yes         *         -         *         -	11 - 16 years								
16-21 years  No  28 (96.6%)  5 (100.0%)  23 (95.8%)  -  -  -  -  -  -  -  -  -  -  -  -  -	No	34 (97.1%)	*	29 (96.7%)	*	-	-	-	-
No         28 (96.6%)         5 (100.0%)         23 (95.8%)         -	Yes	*	-	*	-	-	-	-	-
Yes       *       -       *       -	16 - 21 years								
21 - 31 years	No	28 (96.6%)	5 (100.0%)	23 (95.8%)	-	-	-	-	-
No       23 (95.8%)       9 (100.0%)       14 (93.3%)       - <t< td=""><td>Yes</td><td>*</td><td>-</td><td>*</td><td>-</td><td>-</td><td>-</td><td>-</td><td>-</td></t<>	Yes	*	-	*	-	-	-	-	-
Yes       *       -       *       -	21 - 31 years								
No	No	23 (95.8%)	9 (100.0%)	14 (93.3%)	-	-	-	-	-
No       8 (88.9%)       -       8 (88.9%)       -	Yes	*	-	*	-	-	-	-	-
Yes         *         -         *         -	31 - 41 years								
41 - 51 years	No	8 (88.9%)	-	8 (88.9%)	-	-	-	-	-
No       9 (100.0%)       -       7 (100.0%)       *       -	Yes	*	-	*	-	-	-	-	-
Yes       -	41 - 51 years								
51 - 61 years	No	9 (100.0%)	-	7 (100.0%)	*	-	-	-	-
No       9 (90.0%)       -       6 (85.7%)       *       -       -       -       -       -       -         Yes       *       -       *       -       -       -       -       -       -       -         No       -       -       -       -       -       -       -       -       -       -         Yes       -       -       -       -       -       -       -       -       -       -	Yes	-	-	-	-	-	-	-	-
Yes * - * Yes	51 - 61 years								
> 60 years	No	9 (90.0%)	-	6 (85.7%)	*	-	-	-	-
No         -	Yes	*	-	*	-	-	-	-	-
Yes	> 60 years								
	No	-	-	-	-	-	-	-	-
At least one episode of		-	-	-	-	-	-	-	-
part-time sleeping non- invasive ventilation; n (%)	At least one episode of part-time sleeping non-invasive ventilation; n (%)								
<1 month									
No	No	-	-	-	-	-	-	-	-

Yes	_	_	-	_	_	-	_	_
1 - 3 months								
No	*	*		<del> </del> -	-	1_	_	_
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	*	*	-	-	-	-	-	-

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 full-time invasive ventilation; n (%)								

						1	1	
< 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	-	-	-	-	-	-	-	-
L			·		·			

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	*	*	-	-	-	-	-	-

Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	21 (95.5%)	14 (93.3%)	6 (100.0%)	-	-	-	-	*
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	19 (90.5%)	6 (100.0%)	12 (85.7%)	*	-	-	-	-
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	5 (83.3%)	*	*	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	9 (100.0%)	-	7 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
51 - 61 years								
No	6 (100.0%)	-	*	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
At least one episode of respiratory physiotherapy; n (%)								

	-	F	I	I	I		I	1
< 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	-	-	-	-	-	-	-	-
			<u> </u>					
Yes	7 (100.0%)	*	*	-	-	-	-	-

31 - 41 years	
Yes       *       -       *       -	
A1 - 51 years	
No       -	
Yes       *       -       *       -	
51 - 61 years	
No       -	
Yes       *       -	
No	
No       -	
Yes       *       -       -       *       -	
At least one episode of feeding tube usage; n (%)  < 1 month  No	
feeding tube usage; n (%)	
No	
Yes	
1	
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	*	*	-	-	-	-	*	-
	•	•	•	•		•	•	

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-	-	-	-	-	-	-	-
*	*	-	-	-	-	-	*
-	-	-	-	-	-	-	-
*	*	-	-	-	-	-	-
-	-	-	-	-	-	-	-
22 (100.0%)	15 (100.0%)	6 (100.0%)	-	-	-	-	*
-	-	-	-	-	-	-	-
21 (100.0%)	6 (100.0%)	14 (100.0%)	*	-	-	-	-
-	-	-	-	-	-	-	-
34 (100.0%)	5 (100.0%)	23 (100.0%)	6 (100.0%)	-	-	-	-
-	-	-	-	-	-	-	-
24 (100.0%)	*	18 (100.0%)	5 (100.0%)	-	-	-	-
-	-	-	-	-	-	-	-
13 (100.0%)	*	9 (100.0%)	*	-	-	-	-
-	-	-	-	-	-	-	-
6 (100.0%)	*	*	*	-	-	-	-
-	-	-	-	-	-	-	-
9 (100.0%)	-	7 (100.0%)	*	-	-	-	-
-	-	-	-	-	-	-	-
6 (100.0%)	-	*	*	-	-	-	-
	22 (100.0%) - 21 (100.0%) - 34 (100.0%) - 24 (100.0%) - 6 (100.0%) -			* * * *	100.0%   1		

,			_					
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								

No	10 (27.8%)	*	9 (34.6%)	-	-	-	-	-
Yes	26 (72.2%)	*	17 (65.4%)	6 (100.0%)	-	-	-	-
16 - 21 years								
No	*	*	*	*	-	-	-	-
Yes	20 (87.0%)	*	17 (94.4%)	*	-	-	-	-
21 - 31 years								
No	-	-	-	-	-	-	-	-
Yes	8 (100.0%)	*	6 (100.0%)	-	-	-	-	-
31 - 41 years								
No	*	-	*	-	-	-	-	-
Yes	*	-	*	*	-	-	-	-
41 - 51 years								
No	-	-	-	-	-	-	-	-
Yes	6 (100.0%)	-	6 (100.0%)	-	-	-	-	-
51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	*	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	*	-	-	*	-	-	-	-
Annual number of hospitalisations								
Mean (SD)	1.4 (1)	1.5 (1.7)	1.3 (0.6)	1.1 (0.3)	-	-	*	*
Median [IQR]	1 [1, 1]	1 [1, 1]	1 [1, 1.3]	1 [1, 1]	-	-	*	*
Missing	305 (75.7%)	42 (65.6%)	165 (73.0%)	89 (88.1%)	*	*	-	5 (71.4%)
Event-free survival (death or permanent ventilation)								
Mean (SD)	56.9 (85.6)	29.5 (54.5)	149.8 (104.5)	-	-	-	-	-
Median [IQR]	18 [6.5, 46]	8 [6, 32]	120 [83, 195]	-	-	-	-	-
Missing	381 (94.5%)	47 (73.4%)	221 (97.8%)	101 (100.0%)	*	*	*	7 (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	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								
mellitusith with	-	-	-	-	-	-	-	-
ketoacidosis)								
E46 (Unspecified protein-								
calorie malnutrition)	i -	-	-	-	-	-	-	-
E86.0 (Dehydration)	*	*	-	-	_	_	_	_
	*							
E87.2 (Acidosis)	*	-	*	-	-	-	-	-
E87.6 (Hypokalemia)	_	_	_		_	_	_	_
Евт. в (пурокания)								
F31 (Bipolar disorder)	-	-	-	-	-	-	-	-
F98.9 (Unspecified								
behavioral and emotional								
disorders with onset usually	<del>-</del>	-	-	-	-	-	-	-
occurring in childhood and								
F99 (Mental disorder, not								
otherwise specified)	-	-	-	-	-	-	-	-
C40.9 (Otl. 11)	*	_	_	*	_	_	_	_
G40.8 (Other epilepsy)								
G40.9 (Epilepsy,	i -	_	_	-	-	-	-	-
unspecified)								
G44 (Other headache	1_	_	_	_	_	_	_	_
syndromes)								
G45.9 (Transient cerebral								
ischaemic attack,	-	-	-	-	-	-	-	-
unspecified)								
G81 (Hemiplegia)	-	_	_	_	_	_	_	_
G83.0 (Diplegia of upper								
limbs)	-	-	-	-	-	-	-	-
G97.1 (Other reaction to	i -	_	_	-	-	-	-	-
spinal and lumbar puncture)								
H60.9 (Otitis externa,	1_	_	_	_	_	_	_	_
unspecified)								
H65.0 (Acute serous otitis	ĺ_	_	_	_	_	_	_	_
media)								
I10 (Essential (primary)								
hypertension)		_	_	-	_	_	_	-
I21.9 (Acute myocardial								
infarction, unspecified)	1-	-	-	-	<del>-</del>	<del>-</del>	-	-
I63.9 (Cerebral infarction,								
unspecified)	-	-	-	-	-	-	-	-
I70.2 (Atherosclerosis of								
arteries of extremities)	-	-	-	-	-	-	-	-
·								
I86.3 (Vulval varices)	-	-	-	-	-	-	-	-
J03 (Acute tonsillitis)	-	-	-	-	-	-	-	-
J03.9 (Acute tonsillitis,								
unspecified)	-	-	-	-	-	-	-	-
unspecificu)	L							

IOC O (At								
J06.9 (Acute upper	*							
respiratory infection,	l T	-	Ţ,	-	-	-	-	-
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,								
(Bronchopheumoma,	-	ļ <del>-</del>	ļ <del>-</del>	<del>-</del>	<del>-</del>	-	<del>-</del>	-
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)	-	-	-	-	-	-	-	-
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)	-	-	-	-	-	-	-	-

1,000 0 (C.1. 1 C.		1		I				
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,	, and the second	-		-	-	-	-	-
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	_	-	<b> </b> -	-	<b> </b> -	_	<b> </b> -	_
unspecified ovarian cysts)								
R00.2 (Palpitations)	*	_	*	-	-	-	-	_
R06 (Abnormalities of	*	*	-	-	-	-	-	-
breathing)								
R06.0 (Dyspnoea)	-	-	-	-	-	-	-	-
	*	*						
R09.2 (Respiratory arrest)	7.	,		<u> </u>		<u> </u>		

R11 (Nasses and vounting) R33 (Referation of urine) R34 (Referation of urine) R35 (Referation of urine) R36 (Referation of urine) R37 (Referation of urine) R38 (Referation of urine) R39 (Referation of urine) R30 (Referation of urine) R31 (Referation of urine) R32 (Referation of urine) R33 (Deslocation of urine) R34 (Referation of urine) R35 (Referation of urine) R35 (Referation of urine) R37 (Referation of urine) R37 (Referation of urine) R37 (Referation of urine) R38 (Referation of urine) R39 (Referation of urine) R30 (Referation of urine) R31 (Referation of urine) R32 (Referation of urine) R33 (Referation of urine) R34 (Referation of urine) R35 (Referation of urine) R35 (Referation of urine) R37 (Referation o		1	1	1	1	1		1	1
R31 (Retention of urine)  R41 Is (Other and unspecified symptoms and signs involving cognitive functions and awareness)  R50 9 (Fever, unspecified)  R51 (Headache)  R51 (Headache)  R52 (Febrile convolsions)  R63 3 (Feeding difficulties and mismanagement)  R63 5 (Grebrile convolsions)  R63 5 (Feeding difficulties and mismanagement)  R63 6 (Insufficient intake of food and water)  R52 (Systemic Inflammatory Response Syndrome of non-inflections)  R53 0 (Insufficient intake)  R53 0 (Insufficient intake)  R54 1 (Insufficient intake)  R55 1 (Insufficient intake)  R55 2 (Systemic Inflammatory Response Syndrome of non-inflections)  R55 1 (Insufficient intake)  R55 2 (Insufficient intake)  R57 2 (Insufficient of neck of n	R11 (Nausea and	-	-	-	-	-	-	-	-
### ### ##############################									
unspecified symptoms and wareness signs involving cognitive functions and awareness signs involving control in the signs of the		-	-	-	-	-	-	-	-
signs involving cognitive functions and wareness)  RS0.9 (Fever, unspecified)  RS1 (Headache)  RS1 (Headache)  RS1 (Headache)  RS1 (Headache)  RS1 (Gebrid  RS1 (Headache)  RS2 (Headache)  RS3 (Headache)  RS3 (Headache)  RS3 (Headache)  RS3 (Headache)  RS4 (Headache)  RS5 (Headache)  RS									
functions and awareness	unspecified symptoms and								
R5.9 (Fever, unspecified)	signs involving cognitive	-	-	-	-	-	-	-	-
Unspecified	functions and awareness)								
R51 (Headache)	R50.9 (Fever,								
R56.0 (Fibrile convulsions)	unspecified)	-	_	-	-	-	-	-	
R63.3 (Feeding difficulties and mismanagement)		-	-	-	-	-	-	-	-
R63 of (Insufficient intake of food and water)		_	l_	_	_	_	_	_	<u> </u>
Additional content of the content									
mismanagement)         R6.3 c (Insufficient intake of food and water)         *									
R65.2 (Kystemic Inflammatory Response Syndrome of non-infectious origin without organ failure)  R73.9 (Hypergivaemia, unspecified)  S00.9 (Superficial injury of the da, part unspecified)  S72 (Fracture of femur)  S72 (Fracture of femur)  S73.0 (Fracture of lower end of femur)  S73.0 (Obstead of hip)  S73.0 (Obstead of hip)  S73.0 (Obstead of hip)  S73.0 (Obstead of hip)  S73.0 (Characture of lower end of femur)  S74.0 (Fracture of lower end of femur)  S75.2 (Fracture of lower end of femur)  S75.3 (Characture of lower end of femu		-	-	-	-	-	-	-	-
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 thead, part unspecified)  S36.9 (Injury of unspecified)  S72.0 (Fracture of femur)  S72.0 (Fracture of lower end of femur)  S73.0 (Dislocation of hip)  S73.0 (Dislocation of hip)  S82.9 (Fracture of lower end of femur)  S73.0 (Tracture of lower end of femur)  S74.0 (Tracture of lower end of femur)  S75.0 (Tracture of lower end of femur)  S75.0 (Tracture of lower end of femur)  S77.0 (Tracture of lower end of femur)  S78.0 (Tracture of lower end of femur)  S79.0 (Tracture of lower end of femur)  S70.0 (Tracture of lower end of femur)  S71.0 (Tracture of lower end of femur)  S72.0 (Tracture of lower end of femur)  S73.0 (Tracture of lower end of femur)  S74.0 (Tracture of lower end of femur)  S75.0 (Tracture of lower end of femur)  S75.0 (Tracture of lower end of femur)  S77.0 (Tracture of lower end of femur)  S78.0 (Tracture of lower		*	_	*	_	_	_	_	-
Inflammatory Response Syndrome of non-infections origin without organ failure)         -	of food and water)								
Syndrome of non-infectious origin without organ failures	R65.2 (Systemic								
origin without organ failure)	Inflammatory Response	-	-	-	-	-	_	-	-
R73.9 (Hyperglycaemia, unspecified)									
Inspecified   S00.9 (Superficial injury of fread, part unspecified)   S13.9 (Injury of unspecified)   S13.9 (Injury of unspecified)   S13.9 (Injury of unspecified)   S13.9 (Injury of unspecified)   S13.0 (Injury of unspe									
of head, part unspecified)         - </td <td>unspecified)</td> <td>-</td> <td>-</td> <td>-</td> <td>-</td> <td>-</td> <td>-</td> <td>-</td> <td>-</td>	unspecified)	-	-	-	-	-	-	-	-
S36.9 (Injury of unspecified intra-abdominal organ)	S00.9 (Superficial injury	_	_	_	_	_	_	_	_
unspecified intra-abdominal organ)  S72 (Fracture of femur)  S72.0 (Fracture of neck of femur)  S72.1 (Fracture of neck of femur)  S72.4 (Fracture of lower end of femur)  S73.0 (Dislocation of hip)  S73.0 (Dislocation of hip)  S73.0 (Dislocation of hip)  S74.0 (Fracture of lower end of femur)  S75.0 (Dislocation of hip)  S75.0 (Dislocat	of head, part unspecified)								
S72 (Fracture of femur)   -   -   -   -   -   -   -   -   -	S36.9 (Injury of								
S72 (Fracture of femur)   -   -   -   -   -   -   -   -   -		-	-	-	-	-	-	-	-
S72.0 (Fracture of neck of femur)  S72.4 (Fracture of lower end of femur)  S73.0 (Dislocation of hip)  S73.0 (Dislocation of hip)  S74.0 (Practure of lower end of femur)  S75.0 (Dislocation of hip)  S77.0 (Dislocation of hip)	organ)								
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)  T45.0 (Antiallergic and antiemetic drugs)		-	-	-	-	-	-	-	-
S72.4 (Fracture of lower end of femur)	S72.0 (Fracture of neck of	_	_	_	_	_		_	_
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)  T45.0 (Antiallergic and antiemetic drugs)									
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)  T45.0 (Antiallergic and antiemetic drugs)		_	_	_	_	_	_	_	_
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)  T37 (Other and unspecified injuries of hip and thigh)  T45.0 (Antiallergic and antiemetic drugs)	end of femur)								
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)		-	-	-	-	-	-	-	-
and thigh)  S82.9 (Fracture of lower leg, part unspecified)  T14.2 (Fracture of unspecified body region)  T45.0 (Antiallergic and antiemetic drugs)  * * * * * * * * * * * * * * * * * * *									
S82.9 (Fracture of lower leg, part unspecified)  T14.2 (Fracture of unspecified body region)  T45.0 (Antiallergic and antiemetic drugs)  * * * * * * * * * * * * * * * * * * *	unspecified injuries of hip	-	-	-	-	-	-	-	-
leg, part unspecified)  T14.2 (Fracture of unspecified body region)  T45.0 (Antiallergic and antiemetic drugs)  T45.0 (Antiallergic and antiemetic drugs)									
T14.2 (Fracture of unspecified body region)  T45.0 (Antiallergic and antiemetic drugs)  * * * * * *		-	-	-	-	-	-	-	-
unspecified body region)  T45.0 (Antiallergic and antiemetic drugs)	T14.2 (Fracture of								
antiemetic drugs)	unspecified body region)	т	-	т	т	-	-	-	-
		_	_	_	_	_	_	_	<u> </u>
T73.0 (Effects of hunger)   -   -   -   -   -   -   -	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								
Z47.8 (Other specified	-	-	-	-	-	-	-	-
orthopaedic follow-up care)								
missing	-	-	-	-	-	-	_	-
_								
Causes of hospitalisation -								
Level 2; n (%)								
A02 (Other salmonella								
infections)	<del>-</del>	-	<del>-</del>	<del>-</del>	<del>-</del>	-	<del>-</del>	-
A04 (Other bacterial								
intestinal infections)	-	-	-	-	-	-	-	-
A09 (Other gastroenteritis								
and colitis of infectious and	-	-	-	-	-	-	-	-
unspecified origin)								
A 46 (Emisimalas)	_	_	_	_	_	_	_	_
A46 (Erysipelas)								
B34 (Viral infection of	l_	_	l_	l_	l_	_	_	_
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	-	-	-	-	-	-	-	-
D00 (Odlana 1								
B99 (Other and								
unspecified infectious	-	-	-	-	-	-	-	-
diseases)								
C80 (Malignant neoplasm,								
without specification of	-	l <sub>-</sub>	-	-	-	_	-	_
site)								
D50 (Iron deficiency	-	-	-	-	-	-	-	-
anaemia)								

1								
E08 (Diabetes mellitus due to underlying condition)	-	-	-	-	-	-	-	-
E10 (Type 1 diabetes								
mellitus)	-	-	-	-	-	-	-	-
E46 (Unspecified protein- energy malnutrition)	-	-	-	-	-	-	-	-
	*	*						
E86 (Volume depletion) E87 (Other disorders of	<u> </u>	,	<del>-</del>	-	-	-	<del>-</del>	-
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)	-	-	-	-	1	-	-	-
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)	-	-	-	-	-	-	-	-

T0.5 / 1	1							I
J06 (Acute upper								
respiratory infections of	*		*					
multiple and unspecified		<del>-</del>		-	ļ -	-	-	<del>-</del>
sites)								
J09 (Influenza due to								
identified zoonotic or								
pandemic influenza virus)	-	_	ļ <sup>-</sup>	-	<del>-</del>	-	<del>-</del>	-
J10 (Influenza due to								
identified seasonal influenza	-	-	-	-	-	-	-	-
virus)								
J12 (Viral pneumonia, not	*		*					
elsewhere classified)	"	-	T	-	-	-	-	-
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								
J16 (Fileumonia, 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	l_	_	_	_	_	_	_	_
solids and liquids)								
J80 (Adult respiratory								
distress syndrome)	-	-	-	-	-	-	-	-
J96 (Respiratory failure,								
	-	-	-	-	-	-	-	-
not elsewhere classified)								
J98 (Other respiratory	5 (17.9%)	*	*	_	_	_	_	_
disorders)	3 (17.570)							
K29 (Gastritis and								
duodenitis)	-	-	-	-	-	-	-	-
•								
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
K40 (Inguinal hernia)		-	-	-		-		-
K57 (Diverticular disease	l_	<u>_</u>	_		<u> </u>		<u> </u>	_
of intestine)	<u> </u>	<u> </u>	[-	] <del>-</del>	[-	] <del>-</del>	[-	<u> </u>
K59 (Other functional								
intestinal disorders)	-	-	-	-	-	-	-	-
K63 (Other diseases of								
	-	-	-	-	-	-	-	-
intestine)								

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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)	-	-	-	-	-	-	-	-

720 (I: 1 : C )								1
Z38 (Liveborn infants								
according to place of birth	-	-	-	-	-	-	-	-
and type of delivery)								
Z47 (Other orthopaedic								
follow-up care)	-	-	-	<del>-</del>	-	-	<del>-</del>	<del>-</del>
missing								
	-	_	-	_	-	-	_	_
Causes of hospitalisation -								
Level 3; n (%)								
A (Certain infectious and								
parasitic diseases)	-	-	-	-	-	-	-	-
B (Certain infectious and	*							
parasitic diseases)	*	-	-	*	-	-	-	-
<u> </u>								
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)	[	<u> </u>	-	<u> </u>	-	[	<u> </u>	-
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	Ţ,	-	Ţ,	-	-	-	-	-
connective tissue)								
N (Diseases of the	_	_	_	_	_	_	_	-
genitourinary system)								
R (Symptoms, signs and								
abnormal clinical and	5 (17.9%)	*	*					
laboratory findings, not	[3 (17.970)	·	<u> </u>	-	-	-	-	-
elsewhere classified)								
S (Injury, poisoning and								
certain other consequences	_	<sub>-</sub>	-	<sub>-</sub>	-	_	<sub>-</sub>	_
of external causes)								
T (Injury, poisoning and								
certain other consequences	*		*	*				
of external causes)		<u> </u>			[-	<del>-</del>	<u> </u>	[
or externar causes)								I

TI (C 1 C : 1	ı	1	I	I	ı		ı	1
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)		-		-	-

Median [IQR]	54.1 [42.9, 73.3]	*	51.7 [42.9, 70.4]	-	-	-	-	-
Missing	381 (94.5%)	60 (93.8%)	208 (92.0%)	101 (100.0%)	*	*	*	7 (100.0%)
Score for Belgium ACTIVLIM PRO at genetic report date								
Mean (SD)	-5.2 (3.3)	*	-5.8 (2.5)	-1.7 (4.2)	-	-	-	-
Median [IQR]	-5.6 [-8.1, -3.1]	*	-6.1 [-8.1, -3.6]	-1.9 [-4.6, 2.6]	-	-	-	-
Missing	357 (88.6%)	62 (96.9%)	190 (84.1%)	93 (92.1%)	*	*	*	7 (100.0%)
Best score for Belgium ACTIVLIM PRO								
Mean (SD)	-4.6 (3.6)	*	-5.5 (2.5)	1.4 (2.7)	-	-	-	-
Median [IQR]	-5.3 [-8.1, -2.5]	*	-5.6 [-8.1, -3.2]	2.7 [-0.3, 3.6]	-	-	-	-
Missing	369 (91.6%)	63 (98.4%)	198 (87.6%)	96 (95.0%)	*	*	*	7 (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								

Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-3.3 (3.6)	-	-5 (2.1)	*	-	-	-	-
Median [IQR]	-4.1 [-4.6, -2.1]	-	-4.1 [-6.3, -3.9]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-5.2 (3.1)	*	-5.9 (2)	*	-	-	-	-
Median [IQR]	-5.4 [-8.1, -4.2]	*	-5.4 [-8.1, -4.4]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-6.3 (2.4)	-	-6.1 (2.5)	*	-	-	-	-
Median [IQR]	-8.1 [-8.1, -4.4]	-	-8.1 [-8.1, -4.1]	*	-	-	-	-
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	-	-	-	-	-	-	-	-


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			Spin	raza   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%)	*	1-	_	-
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%)	*	-	-	-

Crawl	*	-	*	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
Roll onto side	*	*	*	-	-	-	-	-
Sit without support	5 (0.5%)	-	5 (1.4%)	-	-	-	-	-
Stand with assistance	*	-	*	-	-	-	-	-
Stand without assistance	*	-	*	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	*	-	*	*	-	-	-	-
Walk with assistance	*	-	*	-	-	-	-	-
Walk without assistance	*	-	-	*	-	-	-	-
Missing	975 (97.2%)	214 (99.5%)	350 (96.4%)	398 (96.8%)	7 (87.5%)	*	*	*
Best achieved motor milestone after treatment; n (%)								
Climb stairs	281 (28.0%)	*	11 (3.0%)	261 (63.5%)	7 (87.5%)	-	-	-
Crawl	63 (6.3%)	*	51 (14.0%)	8 (1.9%)	-	-	-	-
Hold head without support	25 (2.5%)	7 (3.3%)	13 (3.6%)	*	-	-	*	-
Roll onto side	48 (4.8%)	39 (18.1%)	6 (1.7%)	*	-	-	*	-
Sit without support	227 (22.6%)	69 (32.1%)	147 (40.5%)	11 (2.7%)	-	-	-	-
Stand with assistance	43 (4.3%)	17 (7.9%)	26 (7.2%)	-	-	-	-	-
Stand without assistance	9 (0.9%)	-	6 (1.7%)	*	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	94 (9.4%)	*	11 (3.0%)	77 (18.7%)	-	*	-	*
Walk with assistance	77 (7.7%)	14 (6.5%)	62 (17.1%)	*	-	-	-	-
Walk without assistance	40 (4.0%)	8 (3.7%)	11 (3.0%)	19 (4.6%)	*	-	-	*
Missing	96 (9.6%)	51 (23.7%)	19 (5.2%)	25 (6.1%)	-	-	-	*
Height (cm)								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-

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]	-	-	-	-

Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	165.3 (21)	-	150.5 (31.4)	170.9 (9.9)	*	-	-	-
Median [IQR]	168 [159.5, 178]	-	153 [145, 165.5]	172 [163.5, 179.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	160.5 (22.6)	*	148 (29.8)	169.4 (9.6)	*	-	-	-
Median [IQR]	165 [152.8, 172.8]	*	153.5 [145, 161.2]	172 [164, 176.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	171.7 (10)	-	160 (2.8)	173.1 (9.6)	*	-	-	-
Median [IQR]	172.5 [163.2, 180]	-	160 [158, 160]	173.5 [165.5, 181.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	164.2 (23.9)	-	161.3 (6.1)	164.9 (26.2)	-	-	-	-
Median [IQR]	168 [159.8, 172.8]	-	160 [157, 165]	169 [165, 176]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	168.9 (13.2)	-	-	169.7 (13.9)	*	-	-	-
Median [IQR]	168 [161.5, 182.5]	-	-	168 [163, 183]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
Weight (kg)								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	3.9 (0.4)	4.1 (0.3)	-	-	-	-	*	*
Median [IQR]	4 [3.7, 4.1]	4 [4, 4.4]	-	-	-	-	*	*
Missing	*	*	-	-	-	-	-	-
3 - 6 months								

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%)	-	-	-	-	-	-

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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%)	*	-	-	-

51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	35 (100.0%)	-	6 (100.0%)	29 (100.0%)	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	13 (100.0%)	-	-	12 (100.0%)	*	-	-	-
Age at first full-time or part-time wheelchair usage (months)								
Mean (SD)	9.1 (12.1)	2.8 (2.9)	3.7 (3.4)	18.8 (14.9)	*	-	-	*
Median [IQR]	3.5 [2, 11]	2 [2, 3]	2.5 [2, 4]	13 [8, 27]	*	-	-	*
Missing	491 (49.0%)	113 (52.6%)	140 (38.6%)	227 (55.2%)	6 (75.0%)	*	*	*
Number of contractures; r (%)	1							
< 1 month								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
1 - 3 months								
>1	-	-	-	-	-	-	-	-
0	12 (100.0%)	10 (100.0%)	-	-	-	-	*	*
1	-	-	-	-	-	-	-	-
3 - 6 months								
>1	5 (13.2%)	5 (13.2%)	-	-	-	-	-	-
0	32 (84.2%)	32 (84.2%)	-	-	-	-	-	-
1	*	*	-	-	-	-	-	-
6 - 18 months								
>1	11 (8.9%)	8 (8.7%)	*	-	-	-	-	-
0	107 (86.3%)	78 (84.8%)	25 (89.3%)	*	-	*	-	*
1	6 (4.8%)	6 (6.5%)	-	-	-	-	-	-
1.5 - 2 years								

>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%)	-	-	-	-

51 - 61 years								
>1	12 (21.8%)	-	6 (85.7%)	6 (12.5%)	-	-	-	-
0	40 (72.7%)	-	-	40 (83.3%)	-	-	-	-
1	*	-	*	*	-	-	-	-
> 60 years								
>1	*	-	-	*	-	-	-	-
0	19 (82.6%)	-	-	17 (81.0%)	*	-	-	-
1	-	-	-	-	-	-	-	-
Closest score for CHOP-INTEND								
Mean (SD)	33.4 (15.8)	27.7 (13.1)	38.9 (14.1)	37.5 (24.2)	-	-	*	*
Median [IQR]	33 [22.8, 44]	26 [20.5, 36.5]	37 [31, 50]	41 [16.2, 62.8]	-	-	*	*
Missing	815 (81.3%)	124 (57.7%)	285 (78.5%)	397 (96.6%)	8 (100.0%)	*	-	-
Best score for CHOP-INTEND								
Mean (SD)	42.7 (15.5)	40.7 (15.9)	44.5 (14.1)	49.6 (18.7)	-	-	*	*
Median [IQR]	44 [32.8, 55.2]	42.5 [29, 52]	45 [36, 56]	61 [39, 64]	-	-	*	*
Missing	831 (82.9%)	127 (59.1%)	290 (79.9%)	403 (98.1%)	8 (100.0%)	*	*	*
Most recent score for CHOP-INTEND								
< 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)	47 (11.7)	*	*	<u> </u>				*
Median [IQR]	46.5 [46, 52.2]	*	*	-	+	-	-	*
-	40.3 [40, 32.2]			-	<del>-</del>	-	-	
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]	*	-	*	-	-	-	-	-

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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 HFMS(- E)								
Mean (SD)	27 (20.8)	16.2 (18.7)	15.1 (13.8)	38.8 (19.1)	*	-	-	*
Median [IQR]	24 [6, 46.8]	9 [3, 21]	11 [3, 26.2]	44 [24, 54]	*	-	-	*
Missing	649 (64.7%)	170 (79.1%)	231 (63.6%)	240 (58.4%)	*	*	*	*
Best score for HFMS(-E)								
Mean (SD)	31 (21.2)	15.4 (12.9)	19 (15.9)	42.9 (18.6)	*	-	-	*
Median [IQR]	31 [11, 51]	14 [4.2, 25.2]	14 [4, 33]	50 [29, 58]	*	-	-	*
Missing	669 (66.7%)	185 (86.0%)	232 (63.9%)	243 (59.1%)	*	*	*	*
Most recent score for HFMS(-E)								
< 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)	37.4 (23.4)	*	*	-	-	-	-	-
Median [IQR]	35 [15, 64]	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	30.5 (16.8)	20.5 (16.1)	32.6 (12.2)	49.9 (8.3)	-	-	-	*
Median [IQR]	31 [17, 43]	16.5 [8.5, 27.8]	37 [21, 42]	53 [50.5, 54]	-	-	-	*
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	31.5 (19.7)	16.7 (14.5)	24.4 (13.9)	54.2 (13.4)	-	-	-	-
Median [IQR]	32 [18, 44]	17.5 [2.5, 24.5]	24 [12.8, 37]	61 [52, 62.5]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	29.7 (25.8)	*	7.1 (9.3)	45.9 (20.8)	-	-	-	-
Median [IQR]	19 [4, 59]	*	4 [1.2, 7]	56 [23.5, 62]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	26 (22.8)	-	7.9 (13.3)	37.1 (20.1)	-	-	-	-
Median [IQR]	20 [3.2, 50]	-	3 [2, 4.8]	41 [20.2, 56.2]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	33.3 (21.4)	-	4.8 (10.3)	40.1 (16.6)	*	-	-	*
Median [IQR]	35.5 [14.5, 53]	-	1 [-, 2]	44.5 [26.2, 53]	*	-	-	*
Missing	-	-	-	-	-	-	-	-

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31 - 41 years								
Mean (SD)	26.8 (22.1)	-	5.8 (9.7)	35.5 (19.1)	*	-	-	-
Median [IQR]	27 [2.8, 44.2]	-	0.5 [-, 5.5]	37.5 [19.8, 49.5]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	32 (19.3)	-	*	35.1 (18.1)	*	-	-	-
Median [IQR]	34.5 [13, 50]	-	*	40 [24, 50]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	31.3 (19.2)	-	-	31.3 (19.2)	-	-	-	-
Median [IQR]	39 [13, 51]	-	-	39 [13, 51]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for RULM								
Mean (SD)	23.3 (13.1)	12.5 (9.4)	16 (9.7)	31.1 (11)	35 (5.4)	-	-	*
Median [IQR]	23 [12.5, 35]	10 [7.8, 14]	15.5 [10.2, 21]	34 [25, 37]	36 [32, 37.8]	-	-	*
Missing	716 (71.4%)	187 (87.0%)	249 (68.6%)	273 (66.4%)	*	*	*	*
Best score for RULM								
Mean (SD)	25.3 (12.7)	16.5 (11.6)	19 (11.8)	31.9 (9.4)	36.7 (6.6)	-	-	*
Median [IQR]	26.5 [16, 37]	12 [9, 21.8]	18 [11.2, 25]	35 [27, 37]	39 [34, 41.8]	-	-	*
Missing	725 (72.3%)	189 (87.9%)	253 (69.7%)	276 (67.2%)	*	*	*	*
Most recent score for RULM								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-

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-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
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21.4 (8.7)	14.9 (5.7)	24.1 (7.2)	31 (4.7)	-	-	-	-
23 [13, 28]	13 [10.5, 17]	25 [21, 28.5]	34 [28, 34]	-	-	-	-
-	-	-	-	-	-	-	-
25.4 (10.3)	14.4 (10.6)	23.3 (8.1)	34.5 (5.4)	-	-	-	-
27 [18, 36]	9.5 [6.2, 26.5]	24.5 [18, 28]	36 [36, 37]	-	-	-	-
-	-	-	-	-	-	-	-
24.1 (12.6)	*	13.4 (7.8)	32.6 (7.5)	-	-	-	-
23 [12.8, 37]	*	12 [8.8, 17.2]	37 [29.8, 37]	-	-	-	-
-	-	-	-	-	-	-	-
20.5 (11.4)	*	12.5 (7.2)	28.7 (8.2)	-	-	-	-
19 [11, 30]	*	11 [9, 15]	27 [21.5, 37]	-	-	-	-
-	-	-	-	-	-	-	-
	* - 21.4 (8.7) 23 [13, 28] - 25.4 (10.3) 27 [18, 36] - 24.1 (12.6) 23 [12.8, 37] - 20.5 (11.4)						

Mean (SD)	28.3 (11)	-	13.2 (7.3)	33 (6.1)	*	-	-	*
Median [IQR]	31 [22, 36.5]	-	16 [9.2, 18]	35 [29, 37]	*	-	-	*
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	22.9 (14.4)	-	7.7 (7.1)	32.8 (6.9)	*	-	-	-
Median [IQR]	25.5 [12.2, 37]	-	3 [1, 13]	32 [28.5, 37]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
Mean (SD)	31.1 (8.4)	-	*	31.4 (8.7)	*	-	-	-
Median [IQR]	33 [28, 37]	-	*	34.5 [29, 37]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	24.3 (12.6)	-	*	26.7 (11)	-	-	-	-
Median [IQR]	27 [16.8, 36.5]	-	*	32 [19, 37]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Closest score for HINE-2								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	1002 (99.9%)	214 (99.5%)	363 (100.0%)	411 (100.0%)	8 (100.0%)	*	*	*
Best score for HINE-2								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	1002 (99.9%)	214 (99.5%)	363 (100.0%)	411 (100.0%)	8 (100.0%)	*	*	*
Most recent score for HINE-2								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-

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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 MFM32								
Mean (SD)	51.9 (25.8)	*	33.5 (13.7)	70.4 (21.2)	-	-	-	-
Median [IQR]	46 [30, 75]	*	33 [26, 43]	75 [53, 87]	-	-	-	-
Missing	946 (94.3%)	213 (99.1%)	337 (92.8%)	382 (92.9%)	8 (100.0%)	*	*	*
Best score for MFM32								
Mean (SD)	58.4 (25.9)	*	38.7 (13.9)	76.3 (20.2)	-	-	-	-
Median [IQR]	50 [38.5, 84.5]	*	39 [33, 48]	84 [69, 91]	-	-	-	-
Missing	956 (95.3%)	214 (99.5%)	342 (94.2%)	386 (93.9%)	8 (100.0%)	*	*	*
Most recent score for MFM32								

< 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		1			1	1	1	
	-	-	-	-	-	-	-	-
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)	*	-	-	-
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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	-	-	-	-	-	-	-	-

11 - 16 years								
Mean (SD)	402 (138.2)	-	-	402 (138.2)	-	-	-	-
Median [IQR]	429 [264, 513.5]	-	-	429 [264, 513.5]	-	-	-	-
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)	355.2 (90.8)	-	-	355.2 (90.8)	-	-	-	-
Median [IQR]	389.5 [322.2, 429]	-	-	389.5 [322.2, 429]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
Change between scores in HFSM-E in consecutive age classes								
< 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]	-	-	-	-	-	-	-	-
ve i								
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	*	-	-	-	-	-	-

Missing       -         16 - 21 years       -         Mean (SD)       -         Median [IQR]       -         Missing       -         21 - 31 years       -         Mean (SD)       -		*	-	-	<u>-</u>	-	-	-
Mean (SD)         -           Median [IQR]         -           Missing         -           21 - 31 years         -           Mean (SD)         -		*	-	-				
Median [IQR]         -           Missing         -           21 - 31 years         -           Mean (SD)         -		*	-	-				
Missing -  21 - 31 years  Mean (SD) -			-		-	-	-	-
21 - 31 years  Mean (SD) -		-		-	-	-	-	-
Mean (SD) -			-	-	-	-	-	-
	I							
		-	*	-	-	-	-	*
Median [IQR] -		-	*	-	-	-	-	*
Missing -		-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)		-	-	1	1	-	1	-
Median [IQR] -		-	-	1	1	-	1	-
Missing -		-	-	1	1	-	1	-
41 - 51 years								
Mean (SD) *		-	-	*	-	-	-	-
Median [IQR] *		-	-	*	-	-	-	-
Missing -		-	-	1	1	-	1	-
51 - 61 years								
Mean (SD) *		-	*	*	-	-	-	-
Median [IQR] *		-	*	*	-	-	-	-
Missing -		-	-	1	1	-	1	-
> 60 years								
Mean (SD) *		-	-	*	-	-	-	-
Median [IQR] *		-	-	*	-	-	-	-
Missing -		-	-	-	-	-	-	-
Change between scores in RULM in consecutive age classes								
< 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								
11 - 16 years		*						
Mean (SD)	-	*	<del>-</del>	-	-	-	-	-
Median [IQR]	-	"	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years		*						
Mean (SD)	-	*	-	-	-	-	-	-
Median [IQR]	-	<u> </u>	-	-	-	-	-	-

Missing	_	_	_	_	_	_	_	_
21 - 31 years								
Mean (SD)								*
Median [IQR]	-	<u>-</u>	<del>-</del>	-	-	<del>-</del>	-	*
	<u>-</u>	_	_	-	-	<u>-</u>	-	
Missing	<u>-</u>	-	-	-	-	-	-	-
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	-	-	-	-	-	-	-	-
Change between scores in 6MWT in consecutive age classes								
< 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]	-	-	-	-	-	-	-	-
VC.								
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	*	-	-	*	-	-	-	-
Median [IQR]	*	-	-	*	-	-	-	-
		L	L	L	<u> </u>	l	L	

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%)	*	-	-	-	-	-

2 - 6 years								
No	94 (49.5%)	39 (38.6%)	36 (52.9%)	18 (90.0%)	-	-	-	*
Yes	96 (50.5%)	62 (61.4%)	32 (47.1%)	*	-	-	-	-
6 - 11 years								
No	54 (31.6%)	9 (24.3%)	23 (24.7%)	22 (53.7%)	-	-	-	-
Yes	117 (68.4%)	28 (75.7%)	70 (75.3%)	19 (46.3%)	-	-	-	-
11 - 16 years								
No	17 (16.0%)	-	*	15 (35.7%)	-	-	-	-
Yes	89 (84.0%)	10 (100.0%)	52 (96.3%)	27 (64.3%)	-	-	-	-
16 - 21 years								
No	9 (11.0%)	-	-	9 (25.7%)	-	-	-	-
Yes	73 (89.0%)	5 (100.0%)	42 (100.0%)	26 (74.3%)	-	-	-	-
21 - 31 years								
No	30 (34.5%)	-	*	28 (47.5%)	*	-	-	-
Yes	57 (65.5%)	-	26 (96.3%)	31 (52.5%)	-	-	-	-
31 - 41 years								
No	19 (30.2%)	*	-	17 (42.5%)	*	-	-	-
Yes	44 (69.8%)	-	20 (100.0%)	23 (57.5%)	*	-	-	-
41 - 51 years								
No	29 (48.3%)	-	-	27 (56.2%)	*	-	-	-
Yes	31 (51.7%)	-	9 (100.0%)	21 (43.8%)	*	-	-	-
51 - 61 years								
No	27 (60.0%)	-	*	26 (68.4%)	-	-	-	-
Yes	18 (40.0%)		6 (85.7%)	12 (31.6%)	_	-	-	-
> 60 years								
No	16 (76.2%)	-	-	15 (75.0%)	*	-	-	-
Yes	5 (23.8%)	-	-	5 (25.0%)	-	-	-	-
Cobb angle value; n (%)								
< 1 month								

	1	1	1				1	1
<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%)	*	-	-	-	-

>45°	21 (42.0%)	6 (50.0%)	13 (40.6%)	*	-	-	-	-
30-45°	8 (16.0%)	*	7 (21.9%)	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
<30°	8 (17.8%)	*	*	*	-	-	-	*
>45°	30 (66.7%)	*	18 (78.3%)	11 (61.1%)	-	-	-	-
30-45°	7 (15.6%)	*	*	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
<30°	10 (40.0%)	*	*	7 (46.7%)	-	-	-	-
>45°	14 (56.0%)	*	6 (75.0%)	7 (46.7%)	-	-	-	-
30-45°	*	-	-	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
<30°	7 (70.0%)	-	*	6 (85.7%)	-	-	-	-
>45°	*	-	*	*	*	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
<30°	7 (87.5%)	-	*	5 (83.3%)	*	-	-	-
>45°	*	-	-	*	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								
<30°	*	-	*	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
<30°	*	-	-	*	-	-	-	-
>45°	-	-	-	-	-	-	-	-

30-45° - Missing - > 60 years < 30° - > 45° -  Missing -  At least one use of spinal brace ever; n (%)		-	- - -	-	-	-	-	-
> 60 years  <30° >45° 30-45° Missing At least one use of spinal brace ever; n (%)		-	- - -	-	-	-	-	-
<30° - >45° - 30-45° - Missing - At least one use of spinal brace ever; n (%)		-	-	-	-			
>45° - 30-45° - Missing - At least one use of spinal brace ever; n (%)		-	<u>-</u> -	-	-			
30-45° - Missing - At least one use of spinal brace ever; n (%)		-	-	_		-	-	-
Missing - At least one use of spinal brace ever; n (%)		-	-		-	-	-	-
At least one use of spinal brace ever; n (%)		_		-	-	-	-	-
brace ever; n (%)			-	-	-	-	-	-
No 4	159 (45.8%)	65 (30.2%)	173 (47.7%)	217 (52.8%)	*	*	-	-
Yes 1	61 (16.1%)	74 (34.4%)	70 (19.3%)	16 (3.9%)	-	-	-	*
1	383 (38.2%)	76 (35.3%)	120 (33.1%)	178 (43.3%)	5 (62.5%)	-	*	*
Surgery for scoliosis; n (%)								
< 1 month								
No -		-	-	-	-	-	-	-
Yes -		-	-	-	-	-	-	-
1 - 3 months								
No -		-	-	-	-	-	-	-
Yes -		-	-	-	-	-	-	-
3 - 6 months								
No -		-	-	-	-	-	-	-
Yes -		-	-	-	-	-	-	-
6 - 18 months								
No 6	5 (100.0%)	6 (100.0%)	-	-	-	-	-	-
Yes -		-	-	-	-	-	-	-
1.5 - 2 years								
No 1	1 (100.0%)	9 (100.0%)	*	*	-	-	-	-
Yes -		-	-	-	-	-	-	-
2 - 6 years								
No 1	37 (97.2%)	83 (96.5%)	43 (97.7%)	11 (100.0%)	-	-	-	-
Yes *	•	*	*	-	-	-	-	-
6 - 11 years								

No	133 (80.6%)	38 (82.6%)	74 (77.1%)	21 (91.3%)	-	-	-	-
Yes	32 (19.4%)	8 (17.4%)	22 (22.9%)	*	-	-	-	-
11 - 16 years								
No	43 (41.0%)	*	13 (21.3%)	27 (79.4%)	-	-	-	-
Yes	62 (59.0%)	7 (70.0%)	48 (78.7%)	7 (20.6%)	-	-	-	-
16 - 21 years								
No	36 (45.0%)	*	*	29 (80.6%)	-	-	-	-
Yes	44 (55.0%)	*	34 (91.9%)	7 (19.4%)	-	-	-	-
21 - 31 years								
No	46 (58.2%)	*	*	42 (80.8%)	-	-	-	-
Yes	33 (41.8%)	-	23 (88.5%)	10 (19.2%)	-	-	-	-
31 - 41 years								
No	48 (75.0%)	*	12 (54.5%)	34 (85.0%)	*	-	-	-
Yes	16 (25.0%)	-	10 (45.5%)	6 (15.0%)	-	-	-	-
41 - 51 years								
No	44 (83.0%)	-	*	39 (90.7%)	*	-	-	-
Yes	9 (17.0%)	-	5 (55.6%)	*	-	-	-	-
51 - 61 years								
No	38 (90.5%)	-	7 (100.0%)	31 (88.6%)	-	-	-	-
Yes	*	-	-	*	-	-	-	-
> 60 years								
No	21 (100.0%)	-	-	20 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at surgery for scoliosis								
Mean (SD)	20.1 (17.3)	6.2 (4.9)	15.2 (11.6)	31.8 (18.2)	46.8 (12.2)	-	-	*
Median [IQR]	13.5 [6.7, 29.8]	5 [3.3, 7.3]	11.5 [7.4, 18.7]	29 [16.8, 47.3]	43.6 [39.9, 55.1]	-	-	*
Missing	175 (17.4%)	38 (17.7%)	50 (13.8%)	82 (20.0%)	*	*	*	*
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	1003 (100.0%)	215 (100.0%)	363 (100.0%)	411 (100.0%)	8 (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)	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]	*	-	-	-
, e								
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%)	*	-	-	-	-

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%)	-	-	-	-	-	-
	[- (====/=)	(/-)		1	L		L	L

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	*	*	-	*	-	-	-	-
V	(2 (0( 00/)	26 (06 20/)	27 (100 00/)					
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%)	-	-	-	-

	1			1	1	1	1	1
> 60 years			1					
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	*	*	-	-	-	-	-	-

15.0	1							
1.5 - 2 years								
No	64 (98.5%)	62 (98.4%)	*	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	90 (98.9%)	71 (98.6%)	19 (100.0%)	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 11 years								
No	65 (100.0%)	27 (100.0%)	37 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	50 (100.0%)	9 (100.0%)	40 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
16 - 21 years								
No	28 (100.0%)	5 (100.0%)	23 (100.0%)	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
21 - 31 years								
No	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	11 (91.7%)	-	10 (90.9%)	*	-	-	-	-
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 sleeping non-invasive ventilation; n (%)								

< 1 month								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	13 (81.2%)	13 (81.2%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	42 (89.4%)	42 (89.4%)	-	-	-	-	-	-
Yes	5 (10.6%)	5 (10.6%)	-	-	-	-	-	-
6 - 18 months								
No	62 (92.5%)	61 (92.4%)	*	-	-	-	-	-
Yes	5 (7.5%)	5 (7.6%)	-	-	-	-	-	-
1.5 - 2 years								
No	59 (90.8%)	57 (90.5%)	*	-	-	-	-	-
Yes	6 (9.2%)	6 (9.5%)	-	-	-	-	-	-
2 - 6 years								
No	81 (89.0%)	63 (87.5%)	18 (94.7%)	-	-	-	-	-
Yes	10 (11.0%)	9 (12.5%)	*	-	-	-	-	-
6 - 11 years								
No	57 (87.7%)	21 (77.8%)	35 (94.6%)	*	-	-	-	-
Yes	8 (12.3%)	6 (22.2%)	*	-	-	-	-	-
11 - 16 years								
No	48 (96.0%)	8 (88.9%)	39 (97.5%)	*	-	-	-	-
Yes	*	*	*	-	-	-	-	-
16 - 21 years								
No	26 (92.9%)	*	22 (95.7%)	-	-	-	-	-
Yes	*	*	*	-	-	-	-	-
21 - 31 years								
No	12 (100.0%)	-	11 (100.0%)	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-

31 - 41 years								
No	11 (91.7%)	-	10 (90.9%)	*	-	-	-	-
Yes	*	-	*	-	-	-	-	-
41 - 51 years								
No	7 (87.5%)	-	*	*	-	-	-	-
Yes	*	-	-	*	-	-	-	-
51 - 61 years								
No	8 (100.0%)	-	*	7 (100.0%)	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at start of first full- time non-invasive ventilation episode (years)								
Mean (SD)	1.2 (1.2)	1.2 (1.2)	-	-	-	-	-	-
Median [IQR]	0.7 [0.5, 2]	0.7 [0.5, 2]	-	-	-	-	-	-
Missing	994 (99.1%)	206 (95.8%)	363 (100.0%)	411 (100.0%)	8 (100.0%)	*	*	*
At least one episode of any invasive ventilation; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	6 (85.7%)	6 (85.7%)	-	-	-	-	-	-
Yes	*	*	-	-	-	-	-	-
6 - 18 months								
No	*	*	-	-	-	-	-	-
Yes				i	i	1	1	1
res	12 (80.0%)	12 (80.0%)	-	-	-	-	-	-

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%)	-	-	-	-	-	-

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	-	-	-	-	-	-	-	-
At least one episode of part-time 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%)	-	-	-	-	-	-
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%)	*	-	-	-

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-	-	-	-	-	-	-	-
		-	-	-	-	-	-
*	*	-	-	-	-	-	-
25 (83.3%)	24 (82.8%)	*	-	-	-	-	-
5 (16.7%)	5 (17.2%)	-	-	-	-	-	-
37 (68.5%)	33 (66.0%)	*	-	-	-	-	-
17 (31.5%)	17 (34.0%)	-	-	-	-	-	-
36 (59.0%)	28 (57.1%)	8 (66.7%)	-	-	-	-	-
25 (41.0%)	21 (42.9%)	*	-	-	-	-	-
15 (16.5%)	7 (12.1%)	8 (25.0%)	-	-	-	-	-
76 (83.5%)	51 (87.9%)	24 (75.0%)	*	-	-	-	-
11 (16.4%)	*	8 (20.5%)	*	-	-	-	-
56 (83.6%)	22 (91.7%)	31 (79.5%)	*	-	-	-	-
5 (13.5%)	*	*	-	-	-	-	-
32 (86.5%)	*	25 (89.3%)	*	-	-	-	-
*	-	*	-	-	-	-	-
19 (95.0%)	*	14 (93.3%)	*	-	-	-	-
	5 (16.7%)  37 (68.5%)  17 (31.5%)  36 (59.0%)  25 (41.0%)  15 (16.5%)  76 (83.5%)  11 (16.4%)  56 (83.6%)  5 (13.5%)  32 (86.5%)						

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%)	*	-	-	-	-	-

No         6 (10.9%)         6 (12.0%)         -		1	ı	T	ı	1	1	ı	1
Ves         49 (89 1%)         44 (88 0%)         5 (100 0%) <td>2 - 6 years</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td>	2 - 6 years								
6-11 years         Image: Property of the content				-	-	-	-	-	-
No         *         *         .	Yes	49 (89.1%)	44 (88.0%)	5 (100.0%)	-	-	-	-	-
Yes         17 (85.0%)         13 (81.2%)         *         -	6 - 11 years								
11-16 years	No	*	*	-	-	-	-	-	-
No         *	Yes	17 (85.0%)	13 (81.2%)	*	-	-	-	-	-
Yes         8 (80.0%)         *         *         *         - <th< td=""><td>11 - 16 years</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></th<>	11 - 16 years								
16-21 years	No	*	*	-	-	-	-	-	-
No         -	Yes	8 (80.0%)	*	*	*	-	-	-	-
Yes         *         *         *         -	16 - 21 years								
	No	-	-	-	-	-	-	-	-
No         -	Yes	*	*	*	-	-	-	-	-
Yes         *         -         *         -	21 - 31 years								
No	No	-	-	-	-	-	-	-	-
No         -	Yes	*	-	*	-	-	-	-	-
Yes         *         -	31 - 41 years								
Mo	No	-	-	-	-	-	-	-	-
No         -	Yes	*	-	*	-	-	-	-	-
Yes         *         -	41 - 51 years								
Signature   Sign	No	-	-	-	-	-	-	-	-
No         *         -         -         *         -	Yes	*	-	*	*	-	-	-	-
Yes         *         -         *         -	51 - 61 years								
> 60 years	No	*	-	-	*	-	-	-	-
No         -	Yes	*	-	*	-	-	-	-	-
Yes At least one episode of exclusive feeding tube usage; n (%)	> 60 years								
At least one episode of exclusive feeding tube usage; n (%) < 1 month	No	-	-	-	-	-	-	-	-
exclusive feeding tube usage; n (%) < 1 month	Yes	-	-	-	-	-	-	-	-
	At least one episode of exclusive feeding tube usage; n (%)								
No	< 1 month								
	No	-	-	-	-	-	-	-	-

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	*	-	*	-	-	-	-	-

*	-	*	-	-	-	-	-
*	-	-	*	-	-	-	-
*	-	*	*	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
11 (84.6%)	11 (84.6%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
36 (90.0%)	36 (90.0%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
48 (92.3%)	47 (92.2%)	*	-	-	-	-	-
*	*	-	-	-	-	-	-
48 (90.6%)	48 (92.3%)	-	-	-	-	-	-
5 (9.4%)	*	*	-	-	-	-	-
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	-	-	-	-	-	-	-	-

1 - 3 months								
No	5 (100.0%)	*	-	-	-	_	*	_
Yes	-					_	_	_
3 - 6 months								
No	13 (100.0%)	12 (100.0%)	-	*			<u> </u>	_
Yes	-	-					<u> </u>	_
6 - 18 months								
No	48 (100.0%)	38 (100.0%)	9 (100.0%)	*			1_	1_
Yes	-	-	-				1_	1_
1.5 - 2 years								
No No	35 (100.0%)	21 (100.0%)	13 (100.0%)	*			1_	1_
Yes	-	-	-				1_	
2 - 6 years								
No	135 (100.0%)	66 (100.0%)	52 (100.0%)	17 (100.0%)		_	_	_
Yes	-	-	-	-		_	_	_
6 - 11 years								
No No	113 (100.0%)	25 (100.0%)	60 (100.0%)	28 (100.0%)		_	_	_
Yes	-	-	-	-		_	_	_
11 - 16 years								
No	75 (100.0%)	*	38 (100.0%)	33 (100.0%)		_	_	_
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%)	*	-	-	-
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%)	-	-	-	-

	T	1	1	1				
Yes	114 (72.2%)	59 (78.7%)	43 (67.2%)	12 (63.2%)	-	-	-	-
6 - 11 years								
No	31 (24.2%)	10 (31.2%)	15 (22.7%)	6 (20.0%)	-	-	-	-
Yes	97 (75.8%)	22 (68.8%)	51 (77.3%)	24 (80.0%)	-	-	-	-
11 - 16 years								
No	17 (19.8%)	*	7 (15.9%)	7 (20.0%)	-	-	-	-
Yes	69 (80.2%)	*	37 (84.1%)	28 (80.0%)	-	-	-	-
16 - 21 years								
No	17 (28.3%)	-	10 (35.7%)	7 (25.0%)	-	-	-	-
Yes	43 (71.7%)	*	18 (64.3%)	21 (75.0%)	-	-	-	-
21 - 31 years								
No	11 (26.8%)	-	6 (28.6%)	5 (25.0%)	-	-	-	-
Yes	30 (73.2%)	-	15 (71.4%)	15 (75.0%)	-	-	-	-
31 - 41 years								
No	*	-	*	*	-	-	-	-
Yes	21 (87.5%)	-	12 (92.3%)	9 (81.8%)	-	-	-	-
41 - 51 years								
No	5 (17.2%)	-	*	*	-	-	-	-
Yes	24 (82.8%)	-	5 (71.4%)	19 (86.4%)	-	-	-	-
51 - 61 years								
No	*	-	*	-	-	-	-	-
Yes	22 (95.7%)	-	5 (83.3%)	17 (100.0%)	-	-	-	-
> 60 years								
No	*	-	-	*	-	-	-	-
Yes	7 (87.5%)	-	-	5 (83.3%)	*	-	-	-
Annual number of hospitalisations								
Mean (SD)	1.7 (1)	1.9 (1.3)	1.6 (0.9)	1.7 (0.9)	*	-	*	-
Median [IQR]	1 [1, 2]	1.5 [1, 2.4]	1 [1, 2]	1 [1, 2]	*	-	*	-
Missing	598 (59.6%)	112 (52.1%)	199 (54.8%)	276 (67.2%)	6 (75.0%)	*	*	*
Event-free survival (death or permanent ventilation)								

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	_	_		_	_	_	_	<u> </u>
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	-	-	-	-	-	-	-	-
			1		I		I	1
vehicle unspecified)								

C 61 41 T 32	I	F	1	I				
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	*	<sub>-</sub>	*	_	_	_	_	_
to other chapters)								
B99 (Other and								
unspecified infectious	-	-	-	-	-	-	-	-
diseases)								
C80.9 (Malignant								
neoplasm, primary site	-	-	-	-	-	-	-	-
unspecified)								
D50 (Iron deficiency	*	-	*	-	-	-	-	-
anaemia)		l						

	1	1					1	
D50.9 (Iron deficiency anaemia, unspecified)	*	-	*	-	-	-	-	-
E08.1 (Diabetes mellitus due to underlying condition with ketoacidosis)	-	-	-	-	-	-	-	-
E10.1 (Diabetes mellitusith 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)	*	*	1	-	-	1	-	-
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)	*	*	*	-	-	-	-	-

110.0	1		I					1
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)	-	-	-	-	-	1	-	-
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)	-	-	-	-	-	1	-	-
J98.7 (Respiratory infections, not elsewhere classified)	16 (12.4%)	11 (21.6%)	5 (9.6%)	-	-	1	-	-
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)	-	-	-	-	-	-	-	-

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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	*	-	*	-	-	-	-	-
B99 (Other and unspecified infectious diseases)	-	-	-	-	-	-	-	-

C00 (M 1) 1		l	l					
C80 (Malignant neoplasm,								
without specification of	-	-	-	-	-	-	-	-
site)								
D50 (Iron deficiency	*	_	*	_	_	_	_	_
anaemia)								
E08 (Diabetes mellitus		_	_					_
due to underlying condition)								
E10 (Type 1 diabetes	*	*						
mellitus)	, The state of the		_	-	-	-	-	<del>-</del>
E46 (Unspecified protein-	*	*						
energy malnutrition)	Ţ,	Ţ,	-	-	-	-	-	-
E86 (Volume depletion)	-	-	-	-	-	-	-	-
E87 (Other disorders of								
fluid, electrolyte and acid-	*	-	*	-	-	-	-	-
base balance)								
F31 (Bipolar affective	*			*				
disorder)	, T	_	_	, and the second	-	-	-	-
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)			<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	
H65 (Nonsuppurative	*	-	*	-	-	-	-	-
otitis media)								
I10 (Essential (primary)	_	-	-	_	_	_	_	-
hypertension)								
I21 (Acute myocardial	_	<u> </u>	<u> </u>	_	_	_	_	_
infarction)								
I63 (Cerebral infarction)								<u> </u>
I70 (Atherosclerosis)	-	-	-	-	-	-	-	-
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	<b>I</b>	1	<b>I</b>	1	Γ	<b>I</b>	ı	
I86 (Varicose veins of other sites)	*	-	*	-	-	-	-	-
J03 (Acute tonsillitis)	*	-	*	-	-	-	-	-
J06 (Acute upper	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)	-	-	-	-	-	-	-	-

F /- /	ı	T		ı	ı		ı	ı
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,	*	-	-	-	*	-	-	-
N04 (Nephrotic syndrome)	*	-	*	-	-	-	-	-
N20 (Calculus of kidney and ureter)	-	-	-	-	-	1	-	-
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)	*	-	-	*	-	-	-	-

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R41 (Other symptoms and								
signs involving cognitive	*	*	-	-	-	-	-	-
functions and awareness)								
R50 (Fever of other and	*	*	*					
unknown origin)				-	-	-	-	-
	*		*					
R51 (Headache)	T	-	*	-	-	-	-	-
R56 (Convulsions, not	*	*						
elsewhere classified)	i e	[	-	-	-	-	-	-
R63 (Symptoms and signs								
concerning food and fluid	*	l_	*	<u> </u>	_	_	_	_
intake)								
R65 (Systemic								
Inflammatory Response	-	-	-	-	-	-	-	-
Syndrome [SIRS])								
R73 (Elevated blood	*		*					
glucose level)		-		<del>-</del>	<del>-</del>	-	<del>-</del>	-
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								
	7 (5.4%)	*	-	6 (24.0%)	-	-	-	-
body region)		-						
T45 (Poisoning by								
primarily systemic and	_	_	l_	_	_	_	_	_
haematological agents, not		-						
elsewhere classified)								
T73 (Effects of other								
deprivation)	-	-	-	-	-	-	-	-
T81 (Complications of								
	*	<b> </b> *						
procedures, not elsewhere	<u> </u>	[ ·	l <sup>-</sup>	-	-	-	-	-
classified)		-						ļ
U07 (Emergency use of	_	l <sub>-</sub>	l <sub>-</sub>	_	_	_	_	_
U07)								
W79 (Inhalation and								
ingestion of food causing		1						
obstruction of respiratory	-	-	-	-	-	-	-	-
tract)		1						
uaci)	I	I	I	l	I		I	

X770 (O. d. 1: 1 :								
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)	, and the second	-		-	-	-	-	-
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	72 (55.8%)	38 (74.5%)	28 (53.8%)	6 (24.0%)	_	_	_	_
respiratory system)	72 (33.070)	30 (71.370)	20 (33.070)	0 (21.070)				
K (Diseases of the	10 (7.8%)	*	*	5 (20.0%)				
digestive system)	10 (7.870)			3 (20.070)	-	-	-	-
M (Diseases of the								
musculoskeletal system and	5 (3.9%)	-	*	*	*	-	-	-
connective tissue)	` ′							
N (Diseases of the	*		*	*				
genitourinary system)	<b>^</b>	-	<b>^</b>	<b> </b> *	-	-	-	-
R (Symptoms, signs and								
abnormal clinical and								
laboratory findings, not	12 (9.3%)	*	7 (13.5%)	*	-	-	-	-
elsewhere classified)								
S (Injury, poisoning and	5 (2 00/)	*	*					
	5 (3.9%)	ļ <sup></sup>		· ·	-	-	-	-
of external causes)								

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8 (6.2%)	*	-	6 (24.0%)	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
*	-	*	-	-	-	-	-
-	-	-	-	-	-	-	-
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
0	0	0	0	0	*	*	*
41.7 (25.7)	63.1 (19.9)	49.2 (20.5)	20.8 (19)	-	-	-	-
40.1 [18.3, 64.8]	64.5 [46.9, 78.7]	51.1 [36, 67.5]	13.1 [6, 29.7]	-	-	-	-
897 (89.4%)	195 (90.7%)	315 (86.8%)	373 (90.8%)	8 (100.0%)	*	*	*
38.1 (25.9)	60.7 (21.6)	43.8 (20.5)	19.1 (19.6)	-	-	-	-
37.5 [15.5, 60.6]	62.8 [46.9, 77.9]	43.4 [26.6, 62]	10.9 [4.8, 27.7]	-	-	-	-
906 (90.3%)	195 (90.7%)	322 (88.7%)	375 (91.2%)	8 (100.0%)	*	*	*
			-				

Most recent score for Spain PROFuture Mobility and Independence PRO								
Mean (SD)	41.3 (26.3)	60.9 (23.2)	48.6 (20.8)	21.8 (21.1)	-	-	-	-
Median [IQR]	41 [18.4, 63.8]	65.6 [44.1, 80.7]	51.6 [31.5, 65.6]	14.8 [5.4, 29.6]	-	-	-	-
Missing	897 (89.4%)	195 (90.7%)	315 (86.8%)	373 (90.8%)	8 (100.0%)	*	*	*
Score for Belgium ACTIVLIM PRO at genetic report date								
Mean (SD)	-3 (4.4)	*	-6.4 (2.2)	-0.8 (4)	2.1 (1.6)	-	-	-
Median [IQR]	-3.5 [-8.1, 0.8]	*	-8.1 [-8.1, -4.4]	-0.1 [-3.5, 2.3]	2.8 [2.2, 3.1]	-	-	-
Missing	887 (88.4%)	212 (98.6%)	318 (87.6%)	348 (84.7%)	*	*	*	*
Best score for Belgium ACTIVLIM PRO								
Mean (SD)	-2.6 (4.5)	*	-5.9 (2.4)	-0.4 (4.1)	2.3 (1.4)	-	-	-
Median [IQR]	-2.4 [-8.1, 1.2]	*	-6.7 [-8.1, -3.7]	0.1 [-2.5, 2.8]	2.5 [2.2, 2.8]	-	-	-
Missing	894 (89.1%)	212 (98.6%)	322 (88.7%)	351 (85.4%)	*	*	*	*
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]		1			1			
		-	<del> -</del>	<del> -</del>	<del> -</del>	-	-	-
Missing		-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	*	-	*	-	-	-	-	-
Median [IQR]	*	-	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
Mean (SD)	-4.1 (4.4)	*	-5.5 (2.8)	*	-	-	-	-
Median [IQR]	-5.2 [-8.1, -1.5]	*	-6.9 [-8.1, -2.9]	*	-	-	-	-
Missing	-	-	-	-	-	-	-	-
11 - 16 years								
Mean (SD)	-3.3 (5.3)	*	-6.9 (1.6)	1 (4.9)	-	-	-	-
Median [IQR]	-5.7 [-8.1, 2.2]	*	-8.1 [-8.1, -5.6]	3.2 [-1.7, 4.7]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
16 - 21 years								
Mean (SD)	-3.5 (4.7)	-	-6.3 (2.3)	-0.8 (4.8)	-	-	-	-
Median [IQR]	-3.9 [-8.1, -0.9]	-	-8.1 [-8.1, -4]	-0.2 [-3.4, 3.1]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
21 - 31 years								
Mean (SD)	-1.5 (3.4)	-	-6.5 (1.6)	-0.1 (2.2)	*	-	-	-
Median [IQR]	-1 [-3.4, 1.1]	-	-6.8 [-8.1, -5.1]	-0.4 [-1.9, 2.1]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
31 - 41 years								
Mean (SD)	-3.9 (4.3)	-	-7.4 (1.6)	-2.7 (4)	*	-	-	-
Median [IQR]	-5.2 [-8.1, -0.4]	-	-8.1 [-8.1, -8.1]	-2.8 [-6.6, -0.4]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
41 - 51 years								

Mean (SD)	-1.9 (3.7)	_	*	-1.8 (3.2)	*		I	
			*		*	-	-	-
Median [IQR]	-0.3 [-5.6, 0.8]	-	*	-0.1 [-5.6, 0.3]	*	-	-	-
Missing	-	-	-	-	-	-	-	-
51 - 61 years								
Mean (SD)	-4.2 (3.6)	-	-	-4.2 (3.6)	-	-	-	-
Median [IQR]	-4.9 [-8.1, 0.1]	-	-	-4.9 [-8.1, 0.1]	-	-	-	-
Missing	-	-	-	-	-	-	-	-
> 60 years								
Mean (SD)	*	-	-	*	*	-	-	-
Median [IQR]	*	-	-	*	*	-	-	-
Missing	-	-	-	-	-	-	-	-
						1		
						1		

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			Zolge	nsma   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 (%)								

Non-sitter	-	-	-	-	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best achieved motor milestone; n (%)								
Climb stairs	-	-	-	-	-	-	-	-
Crawl	-	-	-	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
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	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best functional status before treatment; n (%)								
Non-sitter	-	-	-	-	-	-	-	-
Sitter	-	-	-	-	-	-	-	-
Walker	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best functional status after treatment; n (%)								
Non-sitter	21 (20.8%)	19 (27.9%)	*	-	-	-	*	-
Sitter	45 (44.6%)	29 (42.6%)	14 (63.6%)	-	-	-	*	-
Walker	21 (20.8%)	8 (11.8%)	7 (31.8%)	*	-	*	*	-
Missing	14 (13.9%)	12 (17.6%)	-	-	-	-	*	-
Best achieved motor milestone before treatment; n (%)								
Climb stairs	-	-	-	-	-	-	-	-

Crawl	-	-	-	-	-	-	-	-
Hold head without support	-	-	-	-	-	-	-	-
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	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best achieved motor milestone after treatment; n (%)								
Climb stairs	5 (5.0%)	-	*	*	-	*	-	-
Crawl	11 (10.9%)	*	6 (27.3%)	-	-	-	*	-
Hold head without support	*	*	-	-	-	-	-	-
Roll onto side	19 (18.8%)	17 (25.0%)	*	-	-	-	*	-
Sit without support	24 (23.8%)	18 (26.5%)	6 (27.3%)	-	-	-	-	-
Stand with assistance	10 (9.9%)	8 (11.8%)	*	-	-	-	-	-
Stand without assistance	-	-	-	-	-	-	-	-
Unknown	-	-	-	-	-	-	-	-
Walk 10 metres without assistance	5 (5.0%)	*	*	-	-	-	-	-
Walk with assistance	7 (6.9%)	*	*	-	-	-	*	-
Walk without assistance	*	*	*	*	-	-	-	-
Missing	14 (13.9%)	12 (17.6%)	-	-	-	-	*	-
Height (cm)								
< 1 month								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-

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1 - 3 months								
Mean (SD)	56.5 (3.9)	*	-	-	-	-	*	-
Median [IQR]	56.5 [54.2, 60.2]	*	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	62.8 (2.2)	*	-	-	-	-	*	-
Median [IQR]	63.5 [61.5, 64.8]	*	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	72.5 (4.9)	72 (5.1)	*	-	-	*	*	-
Median [IQR]	72 [69, 76]	70 [68.5, 75]	*	-	-	*	*	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	81.7 (5.1)	83.5 (5.3)	78 (2.6)	*	-	*	-	-
Median [IQR]	81 [78.2, 84]	83 [80.2, 85.8]	77.5 [75.8, 80.2]	*	-	*	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	93.4 (8.6)	92.7 (8.3)	93.2 (10)	*	-	*	-	-
Median [IQR]	93 [88, 100]	91 [87, 100]	92.5 [85.2, 99.8]	*	-	*	-	-
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	-	-	-	-	-	-	-	-
Weight (kg)								
< 1 month								
Mean (SD)	*	-	-	-	-	-	*	-
Median [IQR]	*	-	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	4.2 (0.6)	*	-	-	-	-	*	-
Median [IQR]	4.2 [4, 4.6]	*	-	-	-	-	*	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								

Mean (SD)	6.1 (0.6)	*	-	-	-	-	*	-
Median [IQR]	6 [5.7, 6.4]	*	-	-	-	-	*	-
Missing	*	*	-	-	-	-	-	-
6 - 18 months								
Mean (SD)	8.6 (1.4)	8.5 (1.4)	*	-	-	*	*	-
Median [IQR]	8.8 [8, 9.7]	8.8 [8, 9.4]	*	-	-	*	*	-
Missing	13 (29.5%)	12 (34.3%)	-	-	-	-	*	-
1.5 - 2 years								
Mean (SD)	10.1 (1.6)	10.4 (1.6)	9.4 (1.1)	*	-	*	-	-
Median [IQR]	10 [9.2, 11]	10 [9.8, 11]	9.3 [8.6, 10.2]	*	-	*	-	-
Missing	7 (22.6%)	7 (33.3%)	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	42.2 (185.4)	12.1 (2.1)	97.4 (305.8)	*	-	*	-	-
Median [IQR]	12.1 [11.2, 14.1]	12 [11, 13]	12.9 [11.5, 14.8]	*	-	*	-	-
Missing	15 (27.3%)	12 (36.4%)	*	-	-	-	-	-
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 first acquisition of the best motor ability								
Mean (SD)	2.1 (1.2)	2 (1.1)	2.8 (1.4)	*	-	*	*	-
Median [IQR]	1.8 [1.2, 3]	1.8 [1.1, 2.8]	2.5 [1.5, 4]	*	-	*	*	-
Missing	22 (21.8%)	19 (27.9%)	*	-	-	-	*	-
Age at first loss of the best motor ability episodes								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	99 (98.0%)	66 (97.1%)	22 (100.0%)	*	-	*	6 (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	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	-	-	-	-	-	-	-	-

51 - 61 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
> 60 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
Age at first full-time or part-time wheelchair usage (months)								
Mean (SD)	2 (0.5)	1.9 (0.5)	2.4 (0.5)	-	-	-	-	-
Median [IQR]	2 [2, 2.1]	2 [1.9, 2]	2.2 [2, 2.8]	-	-	-	-	-
Missing	72 (71.3%)	49 (72.1%)	12 (54.5%)	*	-	*	6 (100.0%)	-
Number of contractures; n (%)								
< 1 month								
>1	-	-	-	-	-	-	-	-
0	*	-	-	-	-	-	*	-
1	-	-	-	-	-	-	-	-
1 - 3 months								
>1	*	*	-	-	-	-	-	-
0	6 (85.7%)	*	-	-	-	-	*	-
1	-	-	-	-	-	-	-	-
3 - 6 months								
>1	*	*	-	-	-	-	-	-
0	9 (90.0%)	7 (87.5%)	-	-	-	-	*	-
1	-	-	-	-	-	-	-	-
6 - 18 months								
>1	-	-	-	-	-	-	-	-
0	40 (90.9%)	32 (91.4%)	*	-	-	*	*	-
1	*	*	*	-	-	-	-	-
1.5 - 2 years								

>1	*	*			1			
0	26 (83.9%)	18 (85.7%)	6 (75.0%)	*	-	*	-	-
	20 (83.9%)	18 (85.7%)	*	*	-	T	-	-
1	*	*	*	<del> -</del>	-	-	-	-
2 - 6 years								
>1	6 (10.9%)	*	*	-	-	-	-	-
0	43 (78.2%)	25 (75.8%)	13 (76.5%)	*	-	*	-	-
1	6 (10.9%)	5 (15.2%)	*	-	-	-	-	-
6 - 11 years								
>1	*	-	*	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	<u> </u> -	-	-	-	-
11 - 16 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
16 - 21 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
21 - 31 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
31 - 41 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
41 - 51 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
	l				1	<del></del>		<del>                                     </del>

51 - 61 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
> 60 years								
>1	-	-	-	-	-	-	-	-
0	-	-	-	-	-	-	-	-
1	-	-	-	-	-	-	-	-
Closest score for CHOP-INTEND								
Mean (SD)	34.2 (16.9)	24.2 (12.9)	49 (9.5)	*	-	*	44.2 (12.6)	-
Median [IQR]	33 [21, 49.5]	22.5 [16, 30.5]	50 [44, 54.5]	*	-	*	41 [36, 52]	-
Missing	50 (49.5%)	38 (55.9%)	8 (36.4%)	*	-	-	*	-
Best score for CHOP-INTEND								
Mean (SD)	48.4 (13.2)	44 (12.4)	58.3 (5.6)	-	-	*	50.4 (15.3)	-
Median [IQR]	53 [39, 60]	46.5 [34.2, 54]	60 [54, 64]	-	-	*	62 [36, 62]	-
Missing	60 (59.4%)	42 (61.8%)	13 (59.1%)	*	-	-	*	-
Most recent score for CHOP-INTEND								
< 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)	46.5 (15.6)	33.9 (9.3)	*	-	-	*	*	-
Median [IQR]	47 [33, 63]	33 [25, 40]	*	-	-	*	*	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	50.9 (10)	47.7 (9.8)	*	-	-	-	-	-
Median [IQR]	53.5 [44.5, 58.2]	47 [40.2, 55.2]	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	51.4 (7.8)	50.5 (6.4)	54 (9.3)	*	-	-	-	-
Median [IQR]	54 [45.5, 55.5]	54 [44.5, 54.5]	54 [50, 62]	*	-	-	-	-
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]	-	-	-	-	-	-	-	-

	1	T			1	1		,
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 HFMS(- E)								
Mean (SD)	32.6 (18.4)	28.9 (24.8)	31.4 (5.5)	*	-	*	*	-
Median [IQR]	32 [22.5, 43.8]	21 [7, 59]	31 [27.5, 36]	*	-	*	*	-
Missing	69 (68.3%)	53 (77.9%)	11 (50.0%)	-	-	-	5 (83.3%)	-
Best score for HFMS(-E)								
Mean (SD)	41 (17.4)	36.3 (22.1)	39.5 (12.2)	*	-	*	*	-
Median [IQR]	41 [33, 53]	38 [12, 59]	37.5 [34, 42.5]	*	-	*	*	-
Missing	76 (75.2%)	57 (83.8%)	14 (63.6%)	-	-	-	5 (83.3%)	-
Most recent score for HFMS(-E)								
< 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)	42.8 (18.9)	*	*	-	-	-	-	-
Median [IQR]	36 [35, 64]	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1.5 - 2 years								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
2 - 6 years								
Mean (SD)	36.6 (15.7)	31.7 (18.5)	38.4 (9.4)	*	-	*	-	-
Median [IQR]	38 [25, 49.2]	33 [13, 41]	38 [32.5, 44.5]	*	-	*	-	-
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	-	-	-	-	-	-	-	-
Closest score for RULM								
Mean (SD)	20.2 (8.5)	*	*	-	-	-	-	-
Median [IQR]	21 [12, 25]	*	*	-	-	-	-	-
Missing	96 (95.0%)	66 (97.1%)	19 (86.4%)	*	-	*	6 (100.0%)	-
Best score for RULM								
Mean (SD)	23.8 (10)	*	*	-	-	-	-	-
Median [IQR]	28 [14, 31]	*	*	-	-	-	-	-
Missing	96 (95.0%)	66 (97.1%)	19 (86.4%)	*	-	*	6 (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								
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	-	-	-	-	-	-	-	-
Closest score for HINE-2								
Mean (SD)	*	*	-	-	-	-	*	-
Median [IQR]	*	*	-	-	-	-	*	-
Missing	99 (98.0%)	67 (98.5%)	22 (100.0%)	*	-	*	5 (83.3%)	-
Best score for HINE-2								
Mean (SD)	*	*	-	-	-	-	*	-
Median [IQR]	*	*	-	-	-	-	*	-
Missing	99 (98.0%)	67 (98.5%)	22 (100.0%)	*	-	*	5 (83.3%)	-
Most recent score for HINE-2								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-

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-	-	-	-	-	-	-	-
	* *						

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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 MFM32								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Best score for MFM32								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Most recent score for MFM32								

< 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]	-	-	-	-	-	-	-	-

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*	-	-	*	-	-	-	-
*	-	-	*	-	-	-	-
100 (99.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
*	-	-	*	-	-	-	-
	* 100 (99.0%)						

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	-	-	-	-	-	-	-	-

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	-	-	-	-	-	-	-	-
Change between scores in HFSM-E in consecutive age classes								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
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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								
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	-	-	-	-	-	-	-	-
Change between scores in RULM in consecutive age classes								
< 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								
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	-	-	-	-	-	-	-	-
Change between scores in 6MWT in consecutive age classes								
< 1 month								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
1 - 3 months								
Mean (SD)	-	-	-	-	-	-	-	-
Median [IQR]	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
3 - 6 months								
Mean (SD)	-	-	-	-	-	-	-	-
L	L			L		L		

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	-	-	-	-	-	-	-	-
44 46								
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)	1.7 (1)	1.7 (1.1)	2 (0.7)	*	-	*	0.3 (0.2)	-
Median [IQR]	1.7 [0.8, 2.2]	1.7 [0.9, 2.1]	2 [1.5, 2.3]	*	-	*	0.2 [0.1, 0.5]	-
Missing	50 (49.5%)	38 (55.9%)	8 (36.4%)	*	-	-	*	-
Age at report of (first) best HFMS(-E) score								
Mean (SD)	2.5 (1.1)	2.3 (1.1)	2.7 (1)	*	-	*	*	-
Median [IQR]	2.5 [1.8, 3]	2 [1.5, 3]	2.7 [2, 3.5]	*	-	*	*	-
Missing	69 (68.3%)	53 (77.9%)	11 (50.0%)	-	-	-	5 (83.3%)	-
Age at report of (first) best RULM right side score								
Mean (SD)	*	*	*	-	-	-	-	-
Median [IQR]	*	*	*	-	-	-	-	-
Missing	98 (97.0%)	66 (97.1%)	21 (95.5%)	*	-	*	6 (100.0%)	-
Age at report of (first) best HINE-2 score								

	1		I	1	ı	1	F
		-	-	-	-		-
*	*	-	-	-	-	*	-
99 (98.0%)	67 (98.5%)	22 (100.0%)	*	-	*	5 (83.3%)	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
*	-	-	*	-	-	-	-
*	-	-	*	-	-	-	-
100 (99.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
*	-	-	-	-	-	*	-
-	-	-	-	-	-	-	-
*	*	-	-	-	-	*	-
-	-	-	-	-	-	-	-
*	*	-	-	-	-	-	-
-	-	-	-	-	-	-	-
16 (64.0%)	11 (57.9%)	*	-	-	-	*	-
		*	_	-	-	-	-
()							
10 (90.9%)	7 (87.5%)	*	-	-	-	-	_
*	*	_	_	-	-	-	_
	99 (98.0%)  101 (100.0%)  *  * 100 (99.0%)  * 16 (64.0%)  9 (36.0%)  10 (90.9%)	*	*	*	*	* * * * *	* * * * * * * * * * * * * * * * * * *

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 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°	-	-	-	-	-	-	-	-

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°	5 (71.4%)	*	*	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
6 - 11 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
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	-	-	-	-	-	-	-	-

	1				1	ı	ı	1
> 60 years								
<30°	-	-	-	-	-	-	-	-
>45°	-	-	-	-	-	-	-	-
30-45°	-	-	-	-	-	-	-	-
Missing	-	-	-	-	-	-	-	-
At least one use of spinal brace ever; n (%)								
No	29 (28.7%)	20 (29.4%)	8 (36.4%)	-	-	-	*	-
Yes	19 (18.8%)	19 (27.9%)	-	-	-	-	-	-
Missing	53 (52.5%)	29 (42.6%)	14 (63.6%)	*	-	*	5 (83.3%)	-
Surgery for scoliosis; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
3 - 6 months								
No	*	*	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	13 (100.0%)	12 (100.0%)	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
1.5 - 2 years								
No	6 (100.0%)	6 (100.0%)	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
2 - 6 years								
No	37 (100.0%)	27 (100.0%)	10 (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 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]	-	-	-	-	-	-	-	-
NC :								
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)	*	-	*	-	-	-	-	-
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	-	-	-	-	-	-	-	-
At least one episode of airway clearance assistance; n (%)								
< 1 month								
No	*	-	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	6 (85.7%)	*	-	-	-	-	*	-
Yes	*	*	-	-	-	-	-	-
3 - 6 months								
No	5 (100.0%)	*	-	-	-	-	*	-
Yes	-	-	-	-	-	-	-	-
6 - 18 months								
No	19 (73.1%)	12 (63.2%)	*	-	-	-	*	-
Yes	7 (26.9%)	7 (36.8%)	-	-	-	-	-	-
1.5 - 2 years								
No	12 (75.0%)	5 (55.6%)	6 (100.0%)	*	-	-	-	-
Yes	*	*	-	-	-	-	-	-
2 - 6 years								
No	20 (58.8%)	6 (33.3%)	10 (83.3%)	*	-	-	-	-
Yes	14 (41.2%)	12 (66.7%)	*	-	-	-	-	-
6 - 11 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
11 - 16 years								
No	-	-	-	-	-	-	-	-

No         -									
No	Yes	-	-	-	-	-	-	-	-
Yes         -	16 - 21 years								
Part	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         -	21 - 31 years								
No	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         -	31 - 41 years								
1-51 years	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         -	41 - 51 years								
State   Stat	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         -	51 - 61 years								
No	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         -	> 60 years								
At least one episode of any non-invasive ventilation; n (%)  At least one episode of any non-invasive ventilation; n (%) No No	No	-	-	-	-	-	-	-	-
No   -   -   -   -   -   -   -   -   -		-	-	-	-	-	-	-	-
(%)         Import the control of	At least one episode of any								
No         -	(%)								
Yes         -	< 1 month								
1 - 3 months         Image: Control of the contro	No	-	-	-	-	-	-	-	-
No         -	Yes	-	-	-	-	-	-	-	-
Yes         *         *         -	1 - 3 months								
3 - 6 months         Second Secon	No	-	-	-	-	-	-	-	-
No         *         *         -	Yes	*	*	-	-	-	-	-	-
Yes 6 (60.0%) 6 (60.0%) 6 - 18 months	3 - 6 months								
6 - 18 months	No		*	-	-	-	-	-	-
	Yes	6 (60.0%)	6 (60.0%)	-	-	-	-	-	-
No  *  *  -  -  -  -  -  -  -	6 - 18 months								
	No	*	*	-	-	-	-	-	-

1.0 (0.1 == ::	1.0 (0.1.75.)						
18 (94.7%)	18 (94.7%)	-	-	-	-	-	-
		-	-	-	-	-	-
12 (63.2%)	12 (63.2%)	-	-	-	-	-	-
6 (24.0%)	6 (24.0%)	-	-	-	-	-	-
19 (76.0%)	19 (76.0%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
	19 (76.0%)	7 (36.8%) 7 (36.8%) 12 (63.2%) 12 (63.2%) 6 (24.0%) 19 (76.0%)  *  -  -  -  -  -  -  -  -  -  -  -  -	7 (36.8%) 7 (36.8%) - 12 (63.2%) - 6 (24.0%) 6 (24.0%) -  *  *  -  -  -  -  -  -  -  -  -  -	7 (36.8%) 7 (36.8%)	7 (36.8%) 7 (36.8%)	7 (36.8%) 7 (36.8%)	7 (36.8%) 7 (36.

37		I						
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	-	-	-	-	-	-	-	-

г								
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								
lie z jems	1	1	1					

	ı	1	ı	ı	ı	1	ı	
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	-	-	-	-	-	-	-	-
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-	-	-	-	-	-	-	-
*	*	-	-	-	-	-	-
-	-	-	-	-	-	-	-
9 (90.0%)	9 (90.0%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
14 (73.7%)	14 (73.7%)	-	-	-	-	-	-
5 (26.3%)	5 (26.3%)	-	-	-	-	-	-
16 (84.2%)	16 (84.2%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
20 (80.0%)	20 (80.0%)	-	-	-	-	-	-
5 (20.0%)	5 (20.0%)	-	-	-	-	-	-
*	*	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
	14 (73.7%) 5 (26.3%) 16 (84.2%) * 20 (80.0%) 5 (20.0%)	* * * * * * * * * * * * * * * * * * *	*	* * *	* * *	* * * *	* * * *

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	-	-	-	-	-	-	-	

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 full-time 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 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	*	*	-	-	-	-	-	-

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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	-	-	-	-	-	-	-	-
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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	1	1	1	-	-	-	-	-
Yes	1	1	1	-	-	-	-	-
16 - 21 years								
No	1	1	1	-	-	-	-	-
Yes	1	1	1	-	-	-	-	-
21 - 31 years								
No	1	1	1	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
31 - 41 years								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
41 - 51 years								

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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 4b								
< 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%)	-	-	-	-	-	-

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 exclusive feeding tube usage; n (%)								
< 1 month								
No	-	-	-	-	-	-	-	-
Yes	-	-	-	-	-	-	-	-
1 - 3 months								
No	-	-	-	-	-	-	-	-

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	-	-	-	-	-	-	-	-
	L	L	l	l	l		I	

	1	T		1		1	ı	
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								

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	-	-	-	-	-	-	-	-
Annual number of hospitalisations								
Mean (SD)	1.4 (0.8)	1.4 (0.9)	1.6 (0.6)	*	-	-	*	-
Median [IQR]	1 [1, 1.3]	1 [1, 1]	1.2 [1, 2]	*	-	-	*	-
Missing	48 (47.5%)	30 (44.1%)	12 (54.5%)	*	-	*	*	-
Event-free survival (death or permanent ventilation)								
Mean (SD)	*	*	-	-	-	-	-	-
Median [IQR]	*	*	-	-	-	-	-	-
Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Causes of death - Level 1; n (%)								
A49.9 (Bacterial infection, unspecified)	-	-	-	-	-	-	-	-

-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
_	_	_	_	_	_	_	_
<del>-</del>	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-
101 (100.0%)	68 (100.0%)	22 (100.0%)	*	-	*	6 (100.0%)	-
-	-	-	-	-	-	-	-

D (C1	I		1	I				
R (Symptoms, signs and								
abnormal clinical and	-	-	-	-	-	-	-	_
laboratory findings, not								
elsewhere classified)								
U (Codes for special	_	_	_	_	_	_	_	_
purposes)								
V (External causes of								
morbidity and mortality)	<u> </u>	-	[-	<u> </u>	[	_	[	-
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	<del>-</del>	-	-	-	-	-	-	-
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)	<u> </u>	-	[-	<u> </u>	[	-	[	-
C80.9 (Malignant		1						
Laconlara missessite								
neoplasm, primary site	-	-	-	-	-	-	-	-
unspecified)								
D50 (Iron deficiency	-	-	-	-	-	-	-	-
anaemia)								
D50.9 (Iron deficiency	_	_	_	_	_	_	_	_
anaemia, unspecified)								
E08.1 (Diabetes mellitus								
due to underlying condition	-	-	-	-	-	-	-	-
with ketoacidosis)								
with Ketoacidosis)			<u> </u>					

E10.1 (Diabetes								
mellitusith with	-	-	-	-	-	-	-	-
ketoacidosis)								
E46 (Unspecified protein-	<u> </u>	_	_	_	_	_	<u> </u>	_
calorie malnutrition)								
E86.0 (Dehydration)	_	_	_	_	_	_	_	_
•								
E87.2 (Acidosis)	-	-	-	•	-	-	-	-
E87.6 (Hypokalemia)	_	_	_		_	_	_	_
F31 (Bipolar disorder)	-	-	-	-	-	-	-	-
F98.9 (Unspecified								
behavioral and emotional								
disorders with onset usually	<u> </u>	-	[	-	[	-	<u> </u>	-
occurring in childhood and								
F99 (Mental disorder, not	_	_				_	_	_
otherwise specified)	_	_	_	-	_	_	_	_
G40.8 (Other epilepsy)	_	_	_		_	_	_	_
G40.8 (Other ephepsy) 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)	-	-	-	-	-	-	-	-
nypertension)								
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,	l <u>.</u>	_	_	_	_	<sub>-</sub>	l <u>.</u>	_
unspecified)								

IOC O (A					I			
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	_	_	_	_	<u> </u>	_	_	_
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,	  -	_	_	_	l <u>.</u>	_	_	_
unspecified)								
J18.9 (Pneumonia,								
J16.9 (Fileumonia,	- 	-	-	-	-	-	-	-
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		1						
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	_	l_	_	_	_	_	_	_
complications)								
M41 (Spalingia)	_	_	_	_	_	_	_	_
M41 (Scoliosis)								
M41.4 (Neuromuscular	-	-	-	-	-	_	-	-
scoliosis)								
M80 (Osteoporosis with		<u>_</u>	_	_	_		_	<u> </u>
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		l_	_	_	_		_	_
syndrome)								
N20 1 (C.1. 1 . 6 . 4 .)	_	_	_	_	_	_	_	_
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)	<u> </u>	-				<u> </u>		-
R06 (Abnormalities of								
breathing)	-	-	-	-	-	-	-	-
<u> </u>								
R06.0 (Dyspnoea)	-	-	ļ <del>-</del>	ļ <del>-</del>	ļ <del>-</del>	-	-	-
R09.2 (Respiratory arrest)	_	-	-	-	-	_	<b> </b> -	-
103.2 (Respiratory arrest)	l	I	I	I	I	l	I	I

	ı		ı	ı	ı		ı	
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	_	<u>-</u>	_	_	_	_	_	<u>-</u>
convulsions)								
R63.3 (Feeding								
difficulties and	-	-	-	-	-	-	-	-
mismanagement)								
R63.6 (Insufficient intake	_	_	_	_	_	_	_	-
of food and water)								
R65.2 (Systemic								
Inflammatory Response	_	<u>-</u>	_	_	_	_	_	_
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	_	<u> </u>	_	_	_		_	_
femur)								
S72.4 (Fracture of lower	_	<u> </u>	_	_	_		_	_
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	_	<sub>-</sub>	_	_	_	_	_	_
antiemetic drugs)								
T73.0 (Effects of hunger)	-	-	-	-	-	-	-	-
	·	L.			·		·	

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								
Z47.8 (Other specified	-	-	-	-	-	-	-	-
orthopaedic follow-up care)								
missing	-	-	-	-	-	-	-	-
Causes of hospitalisation -								
Causes of nospitalisation -								
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	_	l_	_	l_	_	_	_	_
unspecified site)								
B96 (Other specified								
bacterial agents as the cause								
of diseases classified to	-	-	-	-	-	-	-	-
other chapters)								
other chapters)								
B97 (Viral agents as the								<u> </u>
cause of diseases classified	<del>-</del>	-	<del>-</del>	-	-	<del>-</del>	<del>-</del>	-
B99 (Other and								
unspecified infectious	-	-	-	-	-	-	-	-
diseases)								
C80 (Malignant neoplasm,								
without specification of	-	-	-	-	-	-	-	-
site)								
D50 (Iron deficiency								
	-	-	-	-	-	-	-	-
anaemia)								

E08 (Diabetes mellitus								
due to underlying condition)	-	<del>-</del>	-	-	-	-	-	-
E10 (Type 1 diabetes								
mellitus)	-	-	-	-	-	-	-	-
E46 (Unspecified protein-								
energy malnutrition)	-	-	-	-	-	-	-	-
chergy mamutation)								
E86 (Volume depletion)	-	-	-	-	-	-	-	-
E87 (Other disorders of								
fluid, electrolyte and acid-	_	_	_	_	_	_	_	_
base balance)								
F31 (Bipolar affective								
disorder)	-	-	-	-	-	-	-	-
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)	-	<del>-</del>	-	-	-	-	-	-
G45 (Transient cerebral								
ischaemic attacks and	-	-	-	_	-	_	-	_
related syndromes)								
G81 (Hemiplegia)	-	-	-	-	-	-	-	-
G83 (Other paralytic								
syndromes)	-	<del>-</del>	-	-	-	-	-	<del>-</del>
G97 (Postprocedural								
disorders of nervous system,	_	-	_	_	_	_	_	_
not elsewhere classified)								
·								
H60 (Otitis externa)	-	-	-	-	-	-	-	-
H65 (Nonsuppurative								
otitis media)	-	-	-	-	-	-	-	-
I10 (Essential (primary)								
hypertension)	-	-	-	-	-	-	-	-
I21 (Acute myocardial								
121 (Acute myocardial	-	-	-	-	-	-	-	-
infarction)								
I63 (Cerebral infarction)	-	-	-	-	-	-	-	-
I70 (Atherosclerosis)		-		<u> </u>		<u> </u>		-
I86 (Varicose veins of								
other sites)	-	-	-	-	-	-	-	<sup>-</sup>
·								
J03 (Acute tonsillitis)	_	_	_	-		-		-

J06 (Acute upper								
respiratory infections of								
multiple and unspecified	-	-	-	-	-	-	-	-
sites)								
J09 (Influenza due to								
identified zoonotic or								
	-	-	<del>-</del>	<del>-</del>	-	-	-	-
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)	-	-	-	-	-	-	-	-
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	6 (100.0%)	6 (100.0%)	-	-	-	-	-	_
disorders)	(	(						
K29 (Gastritis and								
duodenitis)	-	-	-	-	-	-	-	-
•								
K35 (Acute appendicitis)	-	-	-	-	-	-	-	-
V 40 (Inin -1 hi )		_						
K40 (Inguinal hernia)		1						
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,	-	-	-	-	-	-	-	-
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)	-	-	-	-	-	-	-	-
runctions 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)	-	-	-	-	-	-	-	-

720 /T: 1 : C /		1	1	1	1			1
Z38 (Liveborn infants								
according to place of birth	-	-	-	-	-	-	-	-
and type of delivery)								
Z47 (Other orthopaedic								
follow-up care)	-	-	-	-	<del>-</del>	-	<del>-</del>	<del>-</del>
missing								
	-	ļ <sup>-</sup>	_	_	_	-	_	_
Causes of hospitalisation -								
Level 3; n (%)								
A (Certain infectious and								
parasitic diseases)	-	-	-	-	-	-	-	-
B (Certain infectious and								
parasitic diseases)	-	-	-	-	-	-	-	-
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								
	6 (100.0%)	6 (100.0%)	-	-	-	-	-	-
respiratory system)								
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		1						
laboratory findings, not	-	-	-	-	-	-	-	-
elsewhere classified)								
S (Injury, poisoning and		1						
certain other consequences	-	-	-	-	-	-	-	-
of external causes)								
T (Injury, poisoning and								
certain other consequences	-	-	-	-	-	-	-	-
of external causes)		1						
· · · · · · · · · · · · · · · · · · ·	•		•	•	•		•	•

Duposes	TT/Q 1 0 :1	ı	1	ı	ı	I	I	ı	I
W(External causes of morbidity and	U (Codes for special	-	-	-	-	-	-	-	-
Mobility and mortality									
Transport   Tran	morbidity and mortality)	-	-	-	-	-	-	-	-
Cleators influencing   clean consist with health services   clean consist with heal		_	_	_	_	_	_	_	_
with health services )         Image: Companies of the composition of the co	L (Factors influencing	_	_	_	_	_	_	_	_
Missing   1									
Incidence rate of each   Isted comorbidity (per parliet revers)		-	-	-	-	-	-	-	-
Diabetes   0	Incidence rate of each								
Diabetes         6         7         8         6         6         6         7         8         6         6         7         8         9         8         8         8         8         8         9         8         8         9         8<	listed comorbidity (per								
Fractures									
Hepatotoxicity	Diabetes	0	0	0	*	-	*	0	-
Non-vertebral fractures	Fractures	0	0	0	*	-	*	0	-
Osteoporosis         0 <t< td=""><td>Hepatotoxicity</td><td>0</td><td>0</td><td>0</td><td>*</td><td>-</td><td>*</td><td>0</td><td>-</td></t<>	Hepatotoxicity	0	0	0	*	-	*	0	-
Pulmonary infections	Non-vertebral fractures	0	0	0	*	-	*	0	-
Pulmonary infections	Osteoporosis	0	0	0	*	_	*	0	_
Sleep apnea	_								
Score for Spain   PROFuture Mobility and Independence PRO at genetic report date	Pulmonary infections	0				-	*	0	-
PROFuture Mobility and Independence PRO at genetic report date	Sleep apnea	0	0	0	*	-	*	0	-
Median [IQR]   *	Score for Spain PROFuture Mobility and Independence PRO at genetic report date								
Missing   100 (99.0%)   67 (98.5%)   22 (100.0%)   *	Mean (SD)	*	*	-	-	-	-	-	-
Best score for Spain   PROFuture Mobility and Independence PRO	Median [IQR]	*	*	-	-	-	-	-	-
PROFuture Mobility and Independence PRO         Image: Control of the properties of the	Missing	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Median [IQR]   *   *   *   -   -   -   -   -   -   -	Best score for Spain PROFuture Mobility and Independence PRO								
Missing   100 (99.0%)   67 (98.5%)   22 (100.0%)   *   -   *   6 (100.0%)   -	Mean (SD)	*	*	-	-	-	-	-	-
Most recent score for Spain PROFuture Mobility and Independence PRO	Median [IQR]	*	*	-	-	-	-	-	-
Spain PROFuture Mobility and Independence PRO	1	100 (99.0%)	67 (98.5%)	22 (100.0%)	*	-	*	6 (100.0%)	-
Mean (SD)   *   *   -   -   -   -   -   -	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								

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	-	-	-	-	-	-	-	-