

All   SMA Type						
Indicator	Overall (N = 2188)	SMA Type 1 (N = 432)	SMA Type 2 (N = 914)	SMA Type 3 (N = 779)	SMA Type 4 (N = 22)	SMA Type Other (N = 7)
<b>All - SMN1 testing method (n, %)</b>						
<b>Before 2011</b>						
DNA sequencing	*	-	*	-	-	-
HRM	*	-	-	*	-	-
MLPA	140 (84.8%)	7 (87.5%)	61 (87.1%)	72 (83.7%)	-	-
RFLP	5 (3.0%)	-	5 (7.1%)	-	-	-
ddPCR	*	-	*	*	-	-
qrtPCR	14 (8.5%)	*	*	10 (11.6%)	*	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	46 (93.9%)	5 (100.0%)	22 (88.0%)	18 (100.0%)	*	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	-	*	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	68 (100.0%)	12 (100.0%)	25 (100.0%)	30 (100.0%)	*	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	54 (98.2%)	16 (94.1%)	22 (100.0%)	15 (100.0%)	*	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	*	-	-	-	-
missing	-	-	-	-	-	-
<b>2018</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	42 (100.0%)	5 (100.0%)	15 (100.0%)	16 (100.0%)	*	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2019</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-

MLPA	49 (100.0%)	11 (100.0%)	15 (100.0%)	20 (100.0%)	-	*
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2020</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	36 (97.3%)	9 (100.0%)	13 (92.9%)	12 (100.0%)	*	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	-	*	-	-	-
missing	-	-	-	-	-	-
<b>2021</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	53 (89.8%)	13 (86.7%)	11 (91.7%)	21 (87.5%)	*	*
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	6 (10.2%)	*	*	*	-	-
missing	-	-	-	-	-	-
<b>2022</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	32 (100.0%)	10 (100.0%)	8 (100.0%)	9 (100.0%)	-	*
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2023</b>						
DNA sequencing	-	-	-	-	-	-
HRM	-	-	-	-	-	-
MLPA	*	-	-	-	-	-
RFLP	-	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>All - SMN2 testing method (n, %)</b>						
<b>Before 2011</b>						
DNA sequencing	*	-	*	*	-	-
MLPA	99 (87.6%)	5 (83.3%)	39 (88.6%)	55 (87.3%)	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	11 (9.7%)	*	*	7 (11.1%)	-	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
DNA sequencing	-	-	-	-	-	-

MLPA	25 (96.2%)	*	11 (91.7%)	10 (100.0%)	*	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	-	*	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	33 (97.1%)	8 (100.0%)	14 (100.0%)	10 (90.9%)	*	-
ddPCR	*	-	-	*	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	39 (97.5%)	11 (91.7%)	16 (100.0%)	11 (100.0%)	*	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	*	-	-	-	-
missing	-	-	-	-	-	-
<b>2018</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	25 (100.0%)	*	8 (100.0%)	8 (100.0%)	*	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2019</b>						
DNA sequencing	*	*	-	-	-	-
MLPA	25 (96.2%)	6 (85.7%)	5 (100.0%)	11 (100.0%)	-	*
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2020</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	24 (96.0%)	7 (100.0%)	8 (88.9%)	8 (100.0%)	*	-
ddPCR	-	-	-	-	-	-
qrtPCR	*	-	*	-	-	-
missing	-	-	-	-	-	-
<b>2021</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	38 (88.4%)	11 (91.7%)	6 (85.7%)	15 (88.2%)	*	*
ddPCR	-	-	-	-	-	-
qrtPCR	5 (11.6%)	*	*	*	-	-
missing	-	-	-	-	-	-
<b>2022</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	22 (100.0%)	6 (100.0%)	6 (100.0%)	6 (100.0%)	-	*
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-

<b>2023</b>						
DNA sequencing	-	-	-	-	-	-
MLPA	*	-	-	-	-	-
ddPCR	-	-	-	-	-	-
qrtPCR	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>All - At least one DMT (n, %)</b>						
<b>Before 2011</b>						
No	91 (100.0%)	15 (100.0%)	48 (100.0%)	23 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	389 (100.0%)	64 (100.0%)	175 (100.0%)	145 (100.0%)	-	*
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	853 (97.8%)	135 (91.8%)	389 (98.5%)	321 (99.7%)	*	*
Yes	19 (2.2%)	12 (8.2%)	6 (1.5%)	*	-	-
<b>2017</b>						
No	877 (87.8%)	100 (66.2%)	421 (90.0%)	349 (93.6%)	*	*
Yes	122 (12.2%)	51 (33.8%)	47 (10.0%)	24 (6.4%)	-	-
<b>2018</b>						
No	920 (65.3%)	102 (45.9%)	450 (69.2%)	361 (69.0%)	*	*
Yes	488 (34.7%)	120 (54.1%)	200 (30.8%)	162 (31.0%)	*	-
<b>2019</b>						
No	862 (54.6%)	102 (38.8%)	405 (57.1%)	342 (58.5%)	7 (63.6%)	*
Yes	717 (45.4%)	161 (61.2%)	304 (42.9%)	243 (41.5%)	*	*
<b>2020</b>						
No	794 (46.8%)	86 (30.3%)	384 (49.9%)	311 (50.2%)	7 (58.3%)	*
Yes	901 (53.2%)	198 (69.7%)	385 (50.1%)	308 (49.8%)	5 (41.7%)	*
<b>2021</b>						
No	473 (31.6%)	46 (18.1%)	215 (32.5%)	200 (36.4%)	7 (50.0%)	*
Yes	1023 (68.4%)	208 (81.9%)	447 (67.5%)	350 (63.6%)	7 (50.0%)	*
<b>2022</b>						
No	438 (33.9%)	50 (20.7%)	206 (36.6%)	167 (36.2%)	6 (66.7%)	*
Yes	854 (66.1%)	191 (79.3%)	357 (63.4%)	294 (63.8%)	*	*
<b>2023</b>						
No	330 (42.1%)	36 (26.5%)	154 (45.6%)	128 (44.8%)	*	*
Yes	454 (57.9%)	100 (73.5%)	184 (54.4%)	158 (55.2%)	*	*
<b>All - Taken the drugs listed as comedICATIONS at least once from registry entry (n, %)</b>						
<b>Before 2011</b>						
No	1026 (100.0%)	186 (100.0%)	459 (100.0%)	366 (100.0%)	7 (100.0%)	*
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	1025 (99.9%)	186 (100.0%)	458 (99.8%)	366 (100.0%)	7 (100.0%)	*
Yes	*	-	*	-	-	-
<b>2014 - 2016</b>						
No	948 (92.4%)	176 (94.6%)	414 (90.2%)	343 (93.7%)	7 (100.0%)	*

Yes	78 (7.6%)	10 (5.4%)	45 (9.8%)	23 (6.3%)	-	-
<b>2017</b>						
No	923 (90.0%)	169 (90.9%)	400 (87.1%)	340 (92.9%)	6 (85.7%)	*
Yes	103 (10.0%)	17 (9.1%)	59 (12.9%)	26 (7.1%)	*	-
<b>2018</b>						
No	917 (89.4%)	164 (88.2%)	400 (87.1%)	340 (92.9%)	7 (100.0%)	*
Yes	109 (10.6%)	22 (11.8%)	59 (12.9%)	26 (7.1%)	-	-
<b>2019</b>						
No	929 (90.5%)	166 (89.2%)	404 (88.0%)	347 (94.8%)	7 (100.0%)	*
Yes	97 (9.5%)	20 (10.8%)	55 (12.0%)	19 (5.2%)	-	*
<b>2020</b>						
No	897 (87.4%)	161 (86.6%)	391 (85.2%)	332 (90.7%)	7 (100.0%)	*
Yes	129 (12.6%)	25 (13.4%)	68 (14.8%)	34 (9.3%)	-	-
<b>2021</b>						
No	833 (81.2%)	153 (82.3%)	377 (82.1%)	291 (79.5%)	6 (85.7%)	*
Yes	193 (18.8%)	33 (17.7%)	82 (17.9%)	75 (20.5%)	*	*
<b>2022</b>						
No	937 (91.3%)	168 (90.3%)	422 (91.9%)	334 (91.3%)	7 (100.0%)	*
Yes	89 (8.7%)	18 (9.7%)	37 (8.1%)	32 (8.7%)	-	-
<b>2023</b>						
No	1025 (99.9%)	186 (100.0%)	459 (100.0%)	365 (99.7%)	7 (100.0%)	*
Yes	*	-	-	*	-	-
<b>All - Annual influenza vaccination (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	*	-	*	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	170 (94.4%)	22 (91.7%)	97 (94.2%)	50 (96.2%)	*	-
Yes	10 (5.6%)	*	6 (5.8%)	*	-	-
<b>2017</b>						
No	104 (74.8%)	18 (78.3%)	56 (73.7%)	30 (76.9%)	-	-
Yes	35 (25.2%)	5 (21.7%)	20 (26.3%)	9 (23.1%)	*	-
<b>2018</b>						
No	144 (78.7%)	29 (70.7%)	67 (77.0%)	46 (90.2%)	*	-
Yes	39 (21.3%)	12 (29.3%)	20 (23.0%)	5 (9.8%)	-	-
<b>2019</b>						
No	406 (95.3%)	65 (94.2%)	182 (94.8%)	157 (97.5%)	-	-
Yes	20 (4.7%)	*	10 (5.2%)	*	-	*
<b>2020</b>						
No	414 (93.9%)	64 (94.1%)	184 (92.0%)	161 (95.8%)	*	-
Yes	27 (6.1%)	*	16 (8.0%)	7 (4.2%)	-	-
<b>2021</b>						
No	194 (68.8%)	39 (73.6%)	62 (57.9%)	91 (76.5%)	-	*

Yes	88 (31.2%)	14 (26.4%)	45 (42.1%)	28 (23.5%)	*	-
<b>2022</b>						
No	105 (80.2%)	19 (76.0%)	36 (72.0%)	48 (88.9%)	-	-
Yes	26 (19.8%)	6 (24.0%)	14 (28.0%)	6 (11.1%)	-	-
<b>2023</b>						
No	*	-	-	*	-	-
Yes	-	-	-	-	-	-
<b>All - At least one pneumococcal vaccination (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	*	-	*	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	179 (99.4%)	24 (100.0%)	102 (99.0%)	52 (100.0%)	*	-
Yes	*	-	*	-	-	-
<b>2017</b>						
No	134 (96.4%)	22 (95.7%)	73 (96.1%)	38 (97.4%)	*	-
Yes	5 (3.6%)	*	*	*	-	-
<b>2018</b>						
No	177 (96.7%)	39 (95.1%)	83 (95.4%)	51 (100.0%)	*	-
Yes	6 (3.3%)	*	*	-	-	-
<b>2019</b>						
No	422 (99.1%)	69 (100.0%)	191 (99.5%)	160 (99.4%)	-	-
Yes	*	-	*	*	-	*
<b>2020</b>						
No	436 (98.9%)	67 (98.5%)	198 (99.0%)	166 (98.8%)	*	-
Yes	5 (1.1%)	*	*	*	-	-
<b>2021</b>						
No	266 (94.3%)	50 (94.3%)	102 (95.3%)	111 (93.3%)	*	*
Yes	16 (5.7%)	*	5 (4.7%)	8 (6.7%)	-	-
<b>2022</b>						
No	125 (95.4%)	22 (88.0%)	48 (96.0%)	53 (98.1%)	-	-
Yes	6 (4.6%)	*	*	*	-	-
<b>2023</b>						
No	*	-	-	*	-	-
Yes	-	-	-	-	-	-
<b>All - Pneumococcal vaccination at least once every 5 years (n, %)</b>						
no	992 (45.3%)	179 (41.4%)	445 (48.7%)	355 (45.6%)	7 (31.8%)	*
yes	34 (1.6%)	7 (1.6%)	14 (1.5%)	11 (1.4%)	-	*
missing	1162 (53.1%)	246 (56.9%)	455 (49.8%)	413 (53.0%)	15 (68.2%)	*
<b>All - At least one episode of any ventilation (n, %)</b>						
<b>Before 2011</b>						
No	87 (95.6%)	15 (100.0%)	45 (93.8%)	23 (100.0%)	-	-
Yes	*	-	*	-	-	-

<b>2011 - 2013</b>						
No	355 (91.3%)	52 (81.2%)	157 (89.7%)	142 (97.9%)	-	*
Yes	34 (8.7%)	12 (18.8%)	18 (10.3%)	*	-	-
<b>2014 - 2016</b>						
No	775 (88.9%)	106 (72.1%)	344 (87.1%)	319 (99.1%)	*	*
Yes	97 (11.1%)	41 (27.9%)	51 (12.9%)	*	-	*
<b>2017</b>						
No	846 (84.7%)	91 (60.3%)	382 (81.6%)	366 (98.1%)	*	*
Yes	153 (15.3%)	60 (39.7%)	86 (18.4%)	7 (1.9%)	-	-
<b>2018</b>						
No	1123 (79.8%)	120 (54.1%)	486 (74.8%)	506 (96.7%)	6 (100.0%)	*
Yes	285 (20.2%)	102 (45.9%)	164 (25.2%)	17 (3.3%)	-	-
<b>2019</b>						
No	1259 (79.7%)	139 (52.9%)	537 (75.7%)	564 (96.4%)	11 (100.0%)	*
Yes	320 (20.3%)	124 (47.1%)	172 (24.3%)	21 (3.6%)	-	*
<b>2020</b>						
No	1250 (73.7%)	122 (43.0%)	521 (67.8%)	586 (94.7%)	12 (100.0%)	*
Yes	445 (26.3%)	162 (57.0%)	248 (32.2%)	33 (5.3%)	-	-
<b>2021</b>						
No	1127 (75.3%)	111 (43.7%)	465 (70.2%)	523 (95.1%)	14 (100.0%)	6 (100.0%)
Yes	369 (24.7%)	143 (56.3%)	197 (29.8%)	27 (4.9%)	-	-
<b>2022</b>						
No	996 (77.1%)	125 (51.9%)	405 (71.9%)	441 (95.7%)	9 (100.0%)	*
Yes	296 (22.9%)	116 (48.1%)	158 (28.1%)	20 (4.3%)	-	*
<b>2023</b>						
No	628 (80.1%)	76 (55.9%)	252 (74.6%)	276 (96.5%)	6 (100.0%)	*
Yes	156 (19.9%)	60 (44.1%)	86 (25.4%)	10 (3.5%)	-	-
<b>All - At least one episode of feeding tube usage (n, %)</b>						
<b>Before 2011</b>						
No	91 (100.0%)	15 (100.0%)	48 (100.0%)	23 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	365 (93.8%)	48 (75.0%)	167 (95.4%)	145 (100.0%)	-	*
Yes	24 (6.2%)	16 (25.0%)	8 (4.6%)	-	-	-
<b>2014 - 2016</b>						
No	790 (90.6%)	93 (63.3%)	369 (93.4%)	320 (99.4%)	*	*
Yes	82 (9.4%)	54 (36.7%)	26 (6.6%)	*	-	-
<b>2017</b>						
No	934 (93.5%)	106 (70.2%)	448 (95.7%)	373 (100.0%)	*	*
Yes	65 (6.5%)	45 (29.8%)	20 (4.3%)	-	-	-
<b>2018</b>						
No	1271 (90.3%)	131 (59.0%)	607 (93.4%)	520 (99.4%)	6 (100.0%)	*
Yes	137 (9.7%)	91 (41.0%)	43 (6.6%)	*	-	-
<b>2019</b>						
No	1433 (90.8%)	153 (58.2%)	674 (95.1%)	584 (99.8%)	11 (100.0%)	*
Yes	146 (9.2%)	110 (41.8%)	35 (4.9%)	*	-	-

<b>2020</b>						
No	1541 (90.9%)	175 (61.6%)	725 (94.3%)	618 (99.8%)	12 (100.0%)	*
Yes	154 (9.1%)	109 (38.4%)	44 (5.7%)	*	-	-
<b>2021</b>						
No	1352 (90.4%)	151 (59.4%)	622 (94.0%)	549 (99.8%)	14 (100.0%)	6 (100.0%)
Yes	144 (9.6%)	103 (40.6%)	40 (6.0%)	*	-	-
<b>2022</b>						
No	1176 (91.0%)	150 (62.2%)	540 (95.9%)	460 (99.8%)	9 (100.0%)	*
Yes	116 (9.0%)	91 (37.8%)	23 (4.1%)	*	-	*
<b>2023</b>						
No	730 (93.1%)	92 (67.6%)	329 (97.3%)	285 (99.7%)	6 (100.0%)	*
Yes	54 (6.9%)	44 (32.4%)	9 (2.7%)	*	-	-
<b>All - At least one episode of wheelchair use (n, %)</b>						
<b>Before 2011</b>						
No	40 (44.0%)	13 (86.7%)	16 (33.3%)	10 (43.5%)	-	-
Yes	51 (56.0%)	*	32 (66.7%)	13 (56.5%)	-	-
<b>2011 - 2013</b>						
No	182 (46.8%)	50 (78.1%)	53 (30.3%)	75 (51.7%)	-	*
Yes	207 (53.2%)	14 (21.9%)	122 (69.7%)	70 (48.3%)	-	-
<b>2014 - 2016</b>						
No	314 (36.0%)	91 (61.9%)	81 (20.5%)	136 (42.2%)	*	*
Yes	558 (64.0%)	56 (38.1%)	314 (79.5%)	186 (57.8%)	-	*
<b>2017</b>						
No	369 (36.9%)	79 (52.3%)	117 (25.0%)	167 (44.8%)	*	*
Yes	630 (63.1%)	72 (47.7%)	351 (75.0%)	206 (55.2%)	-	-
<b>2018</b>						
No	509 (36.2%)	120 (54.1%)	162 (24.9%)	217 (41.5%)	*	*
Yes	899 (63.8%)	102 (45.9%)	488 (75.1%)	306 (58.5%)	*	-
<b>2019</b>						
No	622 (39.4%)	135 (51.3%)	198 (27.9%)	270 (46.2%)	9 (81.8%)	*
Yes	957 (60.6%)	128 (48.7%)	511 (72.1%)	315 (53.8%)	*	-
<b>2020</b>						
No	700 (41.3%)	144 (50.7%)	244 (31.7%)	293 (47.3%)	10 (83.3%)	*
Yes	995 (58.7%)	140 (49.3%)	525 (68.3%)	326 (52.7%)	*	-
<b>2021</b>						
No	506 (33.8%)	96 (37.8%)	151 (22.8%)	234 (42.5%)	12 (85.7%)	5 (83.3%)
Yes	990 (66.2%)	158 (62.2%)	511 (77.2%)	316 (57.5%)	*	*
<b>2022</b>						
No	480 (37.2%)	88 (36.5%)	153 (27.2%)	216 (46.9%)	7 (77.8%)	*
Yes	812 (62.8%)	153 (63.5%)	410 (72.8%)	245 (53.1%)	*	*
<b>2023</b>						
No	330 (42.1%)	56 (41.2%)	103 (30.5%)	151 (52.8%)	*	*
Yes	454 (57.9%)	80 (58.8%)	235 (69.5%)	135 (47.2%)	*	*
<b>All - Age at first episode of any ventilation (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	12.8 (12)	3.8 (3.7)	13.3 (10.9)	36.5 (6.5)	-	-



(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	10.2 (12.2)	3.2 (4)	9.8 (9.2)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	11.6 (14.7)	2.5 (4.2)	12.3 (10.6)	43.4 (13.3)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	8.9 (11)	2.9 (4.2)	14.7 (10.7)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	11.3 (15.1)	1.4 (1.3)	21.8 (13.3)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	9.9 (16.2)	0.9 (1)	18.5 (15.4)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	19.3 (16)	8.4 (10)	22.8 (13.6)	43.2 (15.2)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	12.2 (16.5)	3 (5.1)	19 (13.4)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	20.5 (16)	7.8 (7.4)	23 (13.7)	*	-	*
(Median, [LQ, UQ])	-	-	-	*	-	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	19 (14.5)	11.7 (4.6)	18.6 (6.1)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>All - Age at first episode of invasive ventilation (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	7.2 (8.8)	3 (4.2)	9.1 (7.3)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	1.9 (1.7)	1.3 (0.9)	*	-	-	-
(Median, [LQ, UQ])	-	-	*	-	-	-

(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	9.8 (12.6)	4.5 (5.6)	*	*	-	-
(Median, [LQ, UQ])	-	-	*	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	7.5 (9.3)	4.7 (5.4)	*	-	-	-
(Median, [LQ, UQ])	-	-	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	8.9 (19.1)	1.7 (1.3)	-	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	12.1 (21.6)	*	-	*	-	-
(Median, [LQ, UQ])	-	*	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	13.6 (14.5)	10.1 (13.4)	*	*	-	-
(Median, [LQ, UQ])	-	-	*	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	*	*	-	*	-	-
(Median, [LQ, UQ])	*	*	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	19.8 (18.4)	*	*	*	-	*
(Median, [LQ, UQ])	-	*	*	*	-	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	*	*	*	-	-	-
(Median, [LQ, UQ])	*	*	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>All - Age at first episode of feeding tube usage (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	11.3 (10.9)	3.8 (4.3)	16.6 (11)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	10.6 (11.2)	5.2 (5.2)	15.5 (12.7)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	9.1 (12)	4.2 (5.1)	15.4 (12.1)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-

<b>2017</b>						
(Mean, SD)	8.4 (10.7)	4.4 (6.2)	20.6 (12.4)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	10.7 (12.5)	5.9 (6.7)	19.8 (13.5)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	10 (11.6)	6 (7.3)	22.8 (13.6)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	10.7 (12.7)	4.8 (5.7)	21.1 (13.3)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	4.8 (7.1)	2.3 (2.1)	*	-	-	-
(Median, [LQ, UQ])	-	-	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	10.6 (14.1)	4.4 (5)	30.3 (16.4)	*	-	*
(Median, [LQ, UQ])	-	-	-	*	-	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	10.7 (6.9)	9.2 (6.4)	*	-	-	-
(Median, [LQ, UQ])	-	-	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>All - Age at first episode of gastrostomy (years)</b>						
(Mean, SD)	15.8 (8.3)	*	20.4 (4)	-	-	-
(Median, [LQ, UQ])	-	*	-	-	-	-
(Missing, %)	2178 (99.5%)	429 (99.3%)	908 (99.3%)	779 (100.0%)	22 (100.0%)	7 (100.0%)
<b>All - At least one episode of muscular physiotherapy ever (n, %)</b>						
no	171 (7.8%)	14 (3.2%)	76 (8.3%)	78 (10.0%)	*	-
yes	808 (36.9%)	173 (40.0%)	355 (38.8%)	270 (34.7%)	*	*
missing	1209 (55.3%)	245 (56.7%)	483 (52.8%)	431 (55.3%)	16 (72.7%)	*
<b>All - At least one episode of respiratory physiotherapy ever (n, %)</b>						
no	702 (32.1%)	87 (20.1%)	285 (31.2%)	317 (40.7%)	6 (27.3%)	*
yes	277 (12.7%)	100 (23.1%)	146 (16.0%)	31 (4.0%)	-	-
missing	1209 (55.3%)	245 (56.7%)	483 (52.8%)	431 (55.3%)	16 (72.7%)	*
<b>All - At least one episode of contracture management using orthotics ever (n, %)</b>						
no	577 (26.4%)	59 (13.7%)	233 (25.5%)	273 (35.0%)	6 (27.3%)	*
yes	402 (18.4%)	128 (29.6%)	198 (21.7%)	75 (9.6%)	-	-
missing	1209 (55.3%)	245 (56.7%)	483 (52.8%)	431 (55.3%)	16 (72.7%)	*
<b>All - At least one episode of spinal brace ever (n, %)</b>						
no	768 (35.1%)	97 (22.5%)	334 (36.5%)	325 (41.7%)	6 (27.3%)	*

yes	211 (9.6%)	90 (20.8%)	97 (10.6%)	23 (3.0%)	-	-
missing	1209 (55.3%)	245 (56.7%)	483 (52.8%)	431 (55.3%)	16 (72.7%)	*
<b>All - At least one episode of speech therapy ever (n, %)</b>						
no	802 (36.7%)	85 (19.7%)	378 (41.4%)	326 (41.8%)	6 (27.3%)	*
yes	177 (8.1%)	102 (23.6%)	53 (5.8%)	22 (2.8%)	-	-
missing	1209 (55.3%)	245 (56.7%)	483 (52.8%)	431 (55.3%)	16 (72.7%)	*
<b>Treated - Age at first DMT (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	2.8 (3.9)	1.1 (1.1)	4.1 (1.7)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	9 (12.6)	3.3 (5.5)	8.2 (9.8)	21.3 (17.5)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	14.6 (15.2)	3.8 (5)	9.6 (8.4)	24.2 (18)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	14.5 (15.7)	1.1 (2.4)	12 (10.7)	25.4 (17.6)	*	*
(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	19.8 (17.2)	5.5 (9.5)	18.7 (13.7)	29.6 (17.9)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	21.7 (18.8)	4.3 (6.5)	23.2 (16)	31 (19.9)	*	*
(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	20.4 (18.5)	4.9 (8.2)	20.1 (13.9)	29.9 (19.1)	*	*
(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	26.6 (22.1)	*	*	47.3 (11.8)	-	-
(Median, [LQ, UQ])	-	*	*	-	-	-

(Missing, %)	-	-	-	-	-	-
<b>Treated - Patients who received more than one DMT (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	823 (100.0%)	139 (100.0%)	374 (100.0%)	302 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	971 (99.7%)	180 (98.9%)	421 (99.8%)	359 (100.0%)	5 (100.0%)	*
Yes	*	*	*	-	-	-
<b>2020</b>						
No	1058 (96.9%)	191 (91.8%)	458 (96.4%)	397 (100.0%)	6 (100.0%)	*
Yes	34 (3.1%)	17 (8.2%)	17 (3.6%)	-	-	-
<b>2021</b>						
No	1079 (95.8%)	202 (91.4%)	461 (96.4%)	398 (97.3%)	7 (100.0%)	*
Yes	47 (4.2%)	19 (8.6%)	17 (3.6%)	11 (2.7%)	-	-
<b>2022</b>						
No	892 (92.8%)	185 (88.5%)	378 (95.0%)	317 (93.2%)	5 (100.0%)	-
Yes	69 (7.2%)	24 (11.5%)	20 (5.0%)	23 (6.8%)	-	*
<b>2023</b>						
No	561 (98.9%)	108 (94.7%)	231 (100.0%)	209 (100.0%)	*	*
Yes	6 (1.1%)	6 (5.3%)	-	-	-	-
<b>Treated - Treated with nusinersen (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	342 (94.7%)	41 (77.4%)	160 (96.4%)	140 (99.3%)	-	-
Yes	19 (5.3%)	12 (22.6%)	6 (3.6%)	*	-	-
<b>2017</b>						
No	384 (76.6%)	28 (35.4%)	187 (81.3%)	168 (88.0%)	-	-
Yes	117 (23.4%)	51 (64.6%)	43 (18.7%)	23 (12.0%)	-	-
<b>2018</b>						

No	369 (44.8%)	20 (14.4%)	198 (52.9%)	148 (49.0%)	*	-
Yes	454 (55.2%)	119 (85.6%)	176 (47.1%)	154 (51.0%)	*	-
<b>2019</b>						
No	305 (31.3%)	24 (13.2%)	151 (35.8%)	125 (34.8%)	*	*
Yes	669 (68.7%)	158 (86.8%)	271 (64.2%)	234 (65.2%)	*	-
<b>2020</b>						
No	293 (26.8%)	33 (15.9%)	158 (33.3%)	97 (24.4%)	*	*
Yes	799 (73.2%)	175 (84.1%)	317 (66.7%)	300 (75.6%)	5 (83.3%)	-
<b>2021</b>						
No	366 (32.5%)	68 (30.8%)	201 (42.1%)	89 (21.8%)	-	*
Yes	760 (67.5%)	153 (69.2%)	277 (57.9%)	320 (78.2%)	7 (100.0%)	*
<b>2022</b>						
No	415 (43.2%)	100 (47.8%)	197 (49.5%)	109 (32.1%)	*	-
Yes	546 (56.8%)	109 (52.2%)	201 (50.5%)	231 (67.9%)	*	*
<b>2023</b>						
No	306 (54.0%)	59 (51.8%)	128 (55.4%)	108 (51.7%)	*	*
Yes	261 (46.0%)	55 (48.2%)	103 (44.6%)	101 (48.3%)	*	-
<b>Treated - Treated with onasemnogene abeparvovec-xioi (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	821 (99.8%)	138 (99.3%)	373 (99.7%)	302 (100.0%)	*	-
Yes	*	*	*	-	-	-
<b>2019</b>						
No	967 (99.3%)	177 (97.3%)	421 (99.8%)	359 (100.0%)	5 (100.0%)	-
Yes	7 (0.7%)	5 (2.7%)	*	-	-	*
<b>2020</b>						
No	1063 (97.3%)	187 (89.9%)	468 (98.5%)	397 (100.0%)	6 (100.0%)	-
Yes	29 (2.7%)	21 (10.1%)	7 (1.5%)	-	-	*
<b>2021</b>						
No	1065 (94.6%)	183 (82.8%)	460 (96.2%)	406 (99.3%)	7 (100.0%)	*
Yes	61 (5.4%)	38 (17.2%)	18 (3.8%)	*	-	*
<b>2022</b>						
No	885 (92.1%)	157 (75.1%)	382 (96.0%)	336 (98.8%)	5 (100.0%)	*
Yes	76 (7.9%)	52 (24.9%)	16 (4.0%)	*	-	-
<b>2023</b>						

No	525 (92.6%)	88 (77.2%)	225 (97.4%)	205 (98.1%)	*	*
Yes	42 (7.4%)	26 (22.8%)	6 (2.6%)	*	-	-
<b>Treated - Treated with risdiplam (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	496 (99.0%)	79 (100.0%)	226 (98.3%)	190 (99.5%)	-	-
Yes	5 (1.0%)	-	*	*	-	-
<b>2018</b>						
No	791 (96.1%)	139 (100.0%)	351 (93.9%)	294 (97.4%)	*	-
Yes	32 (3.9%)	-	23 (6.1%)	8 (2.6%)	-	-
<b>2019</b>						
No	930 (95.5%)	182 (100.0%)	389 (92.2%)	350 (97.5%)	5 (100.0%)	*
Yes	44 (4.5%)	-	33 (7.8%)	9 (2.5%)	-	-
<b>2020</b>						
No	987 (90.4%)	189 (90.9%)	399 (84.0%)	389 (98.0%)	6 (100.0%)	*
Yes	105 (9.6%)	19 (9.1%)	76 (16.0%)	8 (2.0%)	-	-
<b>2021</b>						
No	882 (78.3%)	185 (83.7%)	312 (65.3%)	373 (91.2%)	7 (100.0%)	*
Yes	244 (21.7%)	36 (16.3%)	166 (34.7%)	36 (8.8%)	-	*
<b>2022</b>						
No	664 (69.1%)	157 (75.1%)	241 (60.6%)	258 (75.9%)	*	-
Yes	297 (30.9%)	52 (24.9%)	157 (39.4%)	82 (24.1%)	*	*
<b>2023</b>						
No	415 (73.2%)	89 (78.1%)	159 (68.8%)	157 (75.1%)	*	-
Yes	152 (26.8%)	25 (21.9%)	72 (31.2%)	52 (24.9%)	*	*
<b>Treated - Treated with nusinersen and onasemnogene (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-
Yes	-	-	-	-	-	-

<b>2018</b>						
No	823 (100.0%)	139 (100.0%)	374 (100.0%)	302 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	972 (99.8%)	180 (98.9%)	422 (100.0%)	359 (100.0%)	5 (100.0%)	*
Yes	*	*	-	-	-	-
<b>2020</b>						
No	1076 (98.5%)	197 (94.7%)	470 (98.9%)	397 (100.0%)	6 (100.0%)	*
Yes	16 (1.5%)	11 (5.3%)	5 (1.1%)	-	-	-
<b>2021</b>						
No	1109 (98.5%)	210 (95.0%)	473 (99.0%)	408 (99.8%)	7 (100.0%)	*
Yes	17 (1.5%)	11 (5.0%)	5 (1.0%)	*	-	-
<b>2022</b>						
No	953 (99.2%)	202 (96.7%)	398 (100.0%)	340 (100.0%)	5 (100.0%)	*
Yes	8 (0.8%)	7 (3.3%)	-	-	-	-
<b>2023</b>						
No	562 (99.1%)	109 (95.6%)	231 (100.0%)	209 (100.0%)	*	*
Yes	5 (0.9%)	5 (4.4%)	-	-	-	-
<b>Treated - Treated with nusinersen and risdiplam (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	823 (100.0%)	139 (100.0%)	374 (100.0%)	302 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	973 (99.9%)	182 (100.0%)	421 (99.8%)	359 (100.0%)	5 (100.0%)	*
Yes	*	-	*	-	-	-
<b>2020</b>						
No	1075 (98.4%)	202 (97.1%)	464 (97.7%)	397 (100.0%)	6 (100.0%)	*
Yes	17 (1.6%)	6 (2.9%)	11 (2.3%)	-	-	-
<b>2021</b>						
No	1098 (97.5%)	214 (96.8%)	467 (97.7%)	399 (97.6%)	7 (100.0%)	*
Yes	28 (2.5%)	7 (3.2%)	11 (2.3%)	10 (2.4%)	-	-
<b>2022</b>						
No	905 (94.2%)	197 (94.3%)	379 (95.2%)	317 (93.2%)	5 (100.0%)	-
Yes	56 (5.8%)	12 (5.7%)	19 (4.8%)	23 (6.8%)	-	*



<b>2023</b>						
No	567 (100.0%)	114 (100.0%)	231 (100.0%)	209 (100.0%)	*	*
Yes	-	-	-	-	-	-
<b>Treated - Treated with onasemnogene and risdiplam (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	823 (100.0%)	139 (100.0%)	374 (100.0%)	302 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	974 (100.0%)	182 (100.0%)	422 (100.0%)	359 (100.0%)	5 (100.0%)	*
Yes	-	-	-	-	-	-
<b>2020</b>						
No	1091 (99.9%)	208 (100.0%)	474 (99.8%)	397 (100.0%)	6 (100.0%)	*
Yes	*	-	*	-	-	-
<b>2021</b>						
No	1124 (99.8%)	220 (99.5%)	477 (99.8%)	409 (100.0%)	7 (100.0%)	*
Yes	*	*	*	-	-	-
<b>2022</b>						
No	954 (99.3%)	204 (97.6%)	397 (99.7%)	340 (100.0%)	5 (100.0%)	*
Yes	7 (0.7%)	5 (2.4%)	*	-	-	-
<b>2023</b>						
No	566 (99.8%)	113 (99.1%)	231 (100.0%)	209 (100.0%)	*	*
Yes	*	*	-	-	-	-
<b>Treated - Treated with nusinersen onasemnogene and risdiplam (n, %)</b>						
<b>Before 2011</b>						
No	20 (100.0%)	*	12 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	131 (100.0%)	14 (100.0%)	62 (100.0%)	54 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	361 (100.0%)	53 (100.0%)	166 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	501 (100.0%)	79 (100.0%)	230 (100.0%)	191 (100.0%)	-	-

Yes	-	-	-	-	-	-
<b>2018</b>						
No	823 (100.0%)	139 (100.0%)	374 (100.0%)	302 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	974 (100.0%)	182 (100.0%)	422 (100.0%)	359 (100.0%)	5 (100.0%)	*
Yes	-	-	-	-	-	-
<b>2020</b>						
No	1092 (100.0%)	208 (100.0%)	475 (100.0%)	397 (100.0%)	6 (100.0%)	*
Yes	-	-	-	-	-	-
<b>2021</b>						
No	1126 (100.0%)	221 (100.0%)	478 (100.0%)	409 (100.0%)	7 (100.0%)	*
Yes	-	-	-	-	-	-
<b>2022</b>						
No	960 (99.9%)	209 (100.0%)	398 (100.0%)	340 (100.0%)	5 (100.0%)	*
Yes	*	-	-	-	-	-
<b>2023</b>						
No	567 (100.0%)	114 (100.0%)	231 (100.0%)	209 (100.0%)	*	*
Yes	-	-	-	-	-	-
<b>Treated - Age at initiation of nusinersen (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	2.8 (3.9)	1.1 (1.1)	4.1 (1.7)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	9 (12.9)	3.4 (5.6)	8.6 (10.7)	22.5 (17.6)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	14.8 (15.6)	3.9 (5)	9.2 (8.6)	24.4 (18.1)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	14.9 (16.1)	1.2 (2.5)	11.9 (11.2)	25.5 (17.6)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	21.2 (18.5)	2.1 (4.7)	15.9 (13.8)	29.6 (18.1)	*	-

(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	22.1 (20.3)	1.5 (3.6)	16.8 (16.7)	30.4 (18.8)	*	*
(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	22.8 (16.7)	*	21.1 (13.2)	28.4 (15.6)	-	-
(Median, [LQ, UQ])	-	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	23.9 (18.1)	*	*	*	-	-
(Median, [LQ, UQ])	-	*	*	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>Treated - Age at initiation of onasemnogene abeparvovec-xioi (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	*	*	-	-	-	-
(Median, [LQ, UQ])	*	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	*	*	-	-	-	-
(Median, [LQ, UQ])	*	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	1.5 (0.7)	1.2 (0.6)	2.1 (0.7)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	1.8 (1.3)	1.2 (0.8)	2.9 (1.3)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-

(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	1.8 (1.5)	2.1 (1.5)	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	*	*	-	-	-	-
(Median, [LQ, UQ])	*	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>Treated - Age at initiation of risdiplam (years)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	*	-	*	-	-	-
(Median, [LQ, UQ])	*	-	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	14.3 (13.3)	3.8 (1.7)	19.5 (13.5)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	15.9 (12)	7.9 (5.2)	17.2 (10.6)	22.8 (14.8)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	12.1 (9.8)	5.5 (3.6)	11.5 (8.1)	17.4 (10.7)	-	*
(Median, [LQ, UQ])	-	-	-	-	-	*
(Missing, %)	-	-	-	-	-	-

<b>2023</b>						
(Mean, SD)	*	*	*	-	-	-
(Median, [LQ, UQ])	*	*	*	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>Zolgensma - Adequate dose regarding weight at administration (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	*	*	-	-	-	-
Yes	-	-	-	-	-	-
<b>2020</b>						
No	7 (100.0%)	*	*	-	-	-
Yes	-	-	-	-	-	-
<b>2021</b>						
No	14 (73.7%)	6 (66.7%)	5 (83.3%)	*	-	-
Yes	5 (26.3%)	*	*	*	-	-
<b>2022</b>						
No	*	*	-	*	-	-
Yes	*	*	*	-	-	-
<b>2023</b>						
No	*	-	-	-	-	-
Yes	*	*	-	-	-	-
<b>Zolgensma - Co-administration of corticosteroids (n, %)</b>						
<b>Before 2011</b>						
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
Yes	-	-	-	-	-	-
<b>2017</b>						
Yes	-	-	-	-	-	-
<b>2018</b>						
Yes	*	-	*	-	-	-

<b>2019</b>						
Yes	*	*	-	-	-	-
<b>2020</b>						
Yes	10 (100.0%)	8 (100.0%)	*	-	-	-
<b>2021</b>						
Yes	31 (100.0%)	18 (100.0%)	9 (100.0%)	*	-	-
<b>2022</b>						
Yes	21 (100.0%)	14 (100.0%)	*	*	-	-
<b>2023</b>						
Yes	*	*	-	-	-	-
<b>Zolgensma - Anti-AAV9 antibody test before Zolgensma administration (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2020</b>						
No	6 (100.0%)	5 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-
<b>2021</b>						
No	9 (50.0%)	5 (55.6%)	*	*	-	-
Yes	9 (50.0%)	*	*	*	-	-
<b>2022</b>						
No	*	*	*	-	-	-
Yes	6 (66.7%)	*	*	-	-	-
<b>2023</b>						
No	-	-	-	-	-	-
Yes	*	*	-	-	-	-
<b>Zolgensma - Positive (&gt;1:50) anti-AAV9 antibody test (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-

<b>2014 - 2016</b>						
No	-	-	-	-	-	-
<b>2017</b>						
No	-	-	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
<b>2019</b>						
No	-	-	-	-	-	-
<b>2020</b>						
No	*	*	-	-	-	-
<b>2021</b>						
No	15 (100.0%)	8 (100.0%)	*	*	-	-
<b>2022</b>						
No	24 (100.0%)	12 (100.0%)	6 (100.0%)	*	-	-
<b>2023</b>						
No	14 (100.0%)	6 (100.0%)	*	*	-	-
<b>Nusinersen - At least one adequate dose (12mg) (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	*	*	*	-	-	-
missing	16 (84.2%)	10 (83.3%)	5 (83.3%)	*	-	-
<b>2017</b>						
No	*	*	-	-	-	-
Yes	24 (20.5%)	13 (25.5%)	9 (20.9%)	*	-	-
missing	92 (78.6%)	37 (72.5%)	34 (79.1%)	21 (91.3%)	-	-
<b>2018</b>						
No	*	*	-	-	-	-
Yes	199 (43.8%)	57 (47.9%)	73 (41.5%)	65 (42.2%)	*	-
missing	254 (55.9%)	61 (51.3%)	103 (58.5%)	89 (57.8%)	-	-
<b>2019</b>						
No	*	*	-	-	-	-
Yes	303 (45.3%)	74 (46.8%)	121 (44.6%)	103 (44.0%)	*	-
missing	365 (54.6%)	83 (52.5%)	150 (55.4%)	131 (56.0%)	-	-
<b>2020</b>						
No	*	*	-	-	-	-
Yes	374 (46.9%)	81 (46.6%)	142 (44.8%)	146 (48.7%)	*	-
missing	423 (53.0%)	92 (52.9%)	175 (55.2%)	154 (51.3%)	*	-
<b>2021</b>						

No	*	*	-	*	-	-
Yes	355 (46.8%)	64 (41.8%)	126 (45.5%)	158 (49.5%)	6 (85.7%)	-
missing	402 (53.0%)	88 (57.5%)	151 (54.5%)	160 (50.2%)	*	*
<b>2022</b>						
No	*	*	-	-	-	-
Yes	196 (35.9%)	34 (31.2%)	71 (35.3%)	89 (38.5%)	*	-
missing	349 (63.9%)	74 (67.9%)	130 (64.7%)	142 (61.5%)	*	*
<b>2023</b>						
No	*	*	-	-	-	-
Yes	91 (34.9%)	18 (32.7%)	32 (31.1%)	39 (38.6%)	*	-
missing	169 (64.8%)	36 (65.5%)	71 (68.9%)	62 (61.4%)	-	-
<b>Nusinersen - Time between genetic report date and first administration (months)</b>						
(Mean, SD)	71.2 (93)	18.4 (40.7)	77.4 (83.1)	97 (109.8)	43.6 (58.8)	*
(Median, [LQ, UQ])	-	-	-	-	-	*
(Missing, %)	117 (11.6%)	21 (9.5%)	39 (10.7%)	57 (13.9%)	-	-
<b>Nusinersen - Treatment duration defined as the time from initiation to last available administration date (months)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	75.9 (14)	72.8 (15.5)	81.5 (9.3)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	61.6 (13.6)	65.7 (8.1)	58.2 (14.6)	58.3 (18.5)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	52.5 (10.5)	51.9 (11.3)	51.9 (12.3)	53.3 (8.2)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2019</b>						
(Mean, SD)	40.2 (11.7)	38.4 (13.5)	38.9 (12.9)	42.6 (8.2)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	31.2 (7.4)	29.2 (10.5)	31.1 (7.6)	31.7 (6.1)	*	-
(Median, [LQ, UQ])	-	-	-	-	*	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	20.6 (5.1)	17.6 (8)	22.7 (4.2)	21 (3.4)	*	*



(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	10.4 (3.8)	*	6.2 (1)	11.1 (3.8)	-	-
(Median, [LQ, UQ])	-	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	2.5 (1.4)	*	*	*	-	-
(Median, [LQ, UQ])	-	*	*	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>Nusinersen - Ongoing nusinersen at their last reported dose (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
No	*	*	-	*	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2018</b>						
No	*	*	*	*	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2019</b>						
No	15 (53.6%)	5 (41.7%)	7 (87.5%)	*	-	-
Yes	8 (28.6%)	7 (58.3%)	*	-	-	-
missing	5 (17.9%)	-	-	5 (62.5%)	-	-
<b>2020</b>						
No	30 (21.6%)	8 (20.5%)	18 (31.0%)	*	-	-
Yes	104 (74.8%)	31 (79.5%)	40 (69.0%)	32 (78.0%)	-	-
missing	5 (3.6%)	-	-	5 (12.2%)	-	-
<b>2021</b>						
No	59 (21.9%)	18 (33.3%)	21 (23.3%)	20 (16.8%)	-	-
Yes	208 (77.0%)	36 (66.7%)	69 (76.7%)	96 (80.7%)	6 (100.0%)	-
missing	*	-	-	*	-	-
<b>2022</b>						
No	74 (24.3%)	17 (29.3%)	23 (22.5%)	31 (22.1%)	-	*
Yes	229 (75.3%)	41 (70.7%)	79 (77.5%)	108 (77.1%)	*	-

missing	*	-	-	*	-	-
<b>2023</b>						
No	-	-	-	-	-	-
Yes	261 (100.0%)	55 (100.0%)	103 (100.0%)	101 (100.0%)	*	-
missing	-	-	-	-	-	-
<b>Nusinersen - Treatment discontinuation (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	8 (100.0%)	6 (100.0%)	*	-	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	34 (97.1%)	15 (100.0%)	15 (100.0%)	*	-	-
Yes	*	-	-	*	-	-
<b>2018</b>						
No	87 (97.8%)	25 (100.0%)	40 (97.6%)	21 (95.5%)	-	-
Yes	*	-	*	*	-	-
<b>2019</b>						
No	119 (88.1%)	29 (87.9%)	56 (86.2%)	33 (91.7%)	-	-
Yes	16 (11.9%)	*	9 (13.8%)	*	-	-
<b>2020</b>						
No	113 (77.9%)	28 (80.0%)	42 (65.6%)	42 (93.3%)	-	-
Yes	32 (22.1%)	7 (20.0%)	22 (34.4%)	*	-	-
<b>2021</b>						
No	70 (56.5%)	17 (51.5%)	20 (46.5%)	31 (67.4%)	-	*
Yes	54 (43.5%)	16 (48.5%)	23 (53.5%)	15 (32.6%)	-	-
<b>2022</b>						
No	-	-	-	-	-	-
Yes	70 (100.0%)	17 (100.0%)	20 (100.0%)	31 (100.0%)	-	*
<b>2023</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>Nusinersen - Reason for treatment discontinuation (n, %)</b>						
<b>Before 2011</b>						
Availability	-	-	-	-	-	-
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Insufficient initial improve	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Scoliosis	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-

missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
Availability	-	-	-	-	-	-
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Insufficient initial improve	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Scoliosis	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
Availability	-	-	-	-	-	-
Elective choice	8 (100.0%)	6 (100.0%)	*	-	-	-
Insufficient benefit	-	-	-	-	-	-
Insufficient initial improve	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Scoliosis	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
Availability	*	-	*	-	-	-
Elective choice	23 (65.7%)	11 (73.3%)	10 (66.7%)	*	-	-
Insufficient benefit	*	-	*	*	-	-
Insufficient initial improve	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Scoliosis	*	*	*	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	*	-	*	*	-	-
missing	*	*	-	-	-	-
<b>2018</b>						
Availability	9 (10.1%)	-	8 (19.5%)	*	-	-
Elective choice	48 (53.9%)	15 (60.0%)	19 (46.3%)	13 (59.1%)	-	-
Insufficient benefit	*	-	*	*	-	-
Insufficient initial improve	*	*	-	*	-	-
Loss of response	*	*	*	*	-	-
Scoliosis	7 (7.9%)	*	*	*	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	9 (10.1%)	-	6 (14.6%)	*	-	-
missing	8 (9.0%)	*	*	-	-	-
<b>2019</b>						
Availability	15 (11.0%)	-	11 (16.7%)	*	-	-
Elective choice	66 (48.5%)	19 (57.6%)	29 (43.9%)	17 (47.2%)	-	-
Insufficient benefit	5 (3.7%)	-	*	*	-	-
Insufficient initial improve	*	*	-	*	-	-

Loss of response	7 (5.1%)	*	*	*	-	-
Scoliosis	10 (7.4%)	5 (15.2%)	*	*	-	-
Side effects from drug	*	-	-	*	-	-
Side effects from procedure	14 (10.3%)	-	9 (13.6%)	5 (13.9%)	-	-
missing	16 (11.8%)	6 (18.2%)	8 (12.1%)	*	-	-
<b>2020</b>						
Availability	17 (11.7%)	-	10 (15.6%)	7 (15.6%)	-	-
Elective choice	76 (52.4%)	21 (60.0%)	31 (48.4%)	23 (51.1%)	-	-
Insufficient benefit	6 (4.1%)	*	*	*	-	-
Insufficient initial improvement	*	*	*	*	-	-
Loss of response	7 (4.8%)	*	*	*	-	-
Scoliosis	7 (4.8%)	*	*	*	-	-
Side effects from drug	*	-	-	*	-	-
Side effects from procedure	10 (6.9%)	-	5 (7.8%)	5 (11.1%)	-	-
missing	17 (11.7%)	7 (20.0%)	9 (14.1%)	*	-	-
<b>2021</b>						
Availability	9 (7.3%)	-	*	6 (13.0%)	-	-
Elective choice	74 (59.7%)	20 (60.6%)	27 (62.8%)	25 (54.3%)	-	*
Insufficient benefit	*	-	*	*	-	-
Insufficient initial improvement	*	*	*	*	-	-
Loss of response	6 (4.8%)	*	*	*	-	-
Scoliosis	6 (4.8%)	*	*	*	-	-
Side effects from drug	*	-	-	*	-	-
Side effects from procedure	6 (4.8%)	-	*	*	-	-
missing	13 (10.5%)	7 (21.2%)	*	*	-	-
<b>2022</b>						
Availability	*	-	-	*	-	-
Elective choice	52 (74.3%)	13 (76.5%)	15 (75.0%)	22 (71.0%)	-	*
Insufficient benefit	-	-	-	-	-	-
Insufficient initial improvement	*	-	*	*	-	-
Loss of response	*	-	*	-	-	-
Scoliosis	*	*	-	-	-	-
Side effects from drug	*	-	-	*	-	-
Side effects from procedure	*	-	*	*	-	-
missing	*	*	*	*	-	-
<b>2023</b>						
Availability	-	-	-	-	-	-
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Insufficient initial improvement	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Scoliosis	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>Nusinersen - Treatment duration in patients with treatment discontinuation (months)</b>						

<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	8 (100.0%)	6 (100.0%)	*	-	-	-
<b>2017</b>						
(Mean, SD)	*	-	-	*	-	-
(Median, [LQ, UQ])	*	-	-	*	-	-
(Missing, %)	34 (97.1%)	15 (100.0%)	15 (100.0%)	*	-	-
<b>2018</b>						
(Mean, SD)	*	-	*	*	-	-
(Median, [LQ, UQ])	*	-	*	*	-	-
(Missing, %)	87 (97.8%)	25 (100.0%)	40 (97.6%)	21 (95.5%)	-	-
<b>2019</b>						
(Mean, SD)	11.5 (11.9)	*	9.7 (10.7)	*	-	-
(Median, [LQ, UQ])	-	*	-	*	-	-
(Missing, %)	119 (88.1%)	29 (87.9%)	56 (86.2%)	33 (91.7%)	-	-
<b>2020</b>						
(Mean, SD)	22.3 (10.4)	18.7 (15.5)	23.3 (8.6)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	113 (77.9%)	28 (80.0%)	42 (65.6%)	42 (93.3%)	-	-
<b>2021</b>						
(Mean, SD)	31.6 (14.5)	33.1 (18.4)	31.9 (13.7)	29.7 (10.3)	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	70 (56.5%)	17 (51.5%)	20 (46.5%)	31 (67.4%)	-	*
<b>2022</b>						
(Mean, SD)	37.7 (15.8)	45.3 (18.9)	40.1 (14)	32.6 (12.2)	-	*
(Median, [LQ, UQ])	-	-	-	-	-	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>Risdiplam - At least one adequate dose regarding age and weight (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-

Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	*	*	-	-	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	*	-	*	-	-	-
Yes	*	-	*	-	-	-
<b>2020</b>						
No	5 (55.6%)	*	*	-	-	-
Yes	*	*	*	-	-	-
<b>2021</b>						
No	34 (81.0%)	11 (100.0%)	15 (71.4%)	7 (100.0%)	-	-
Yes	7 (16.7%)	-	6 (28.6%)	-	-	-
<b>2022</b>						
No	13 (76.5%)	6 (75.0%)	*	*	*	-
Yes	*	*	*	-	-	-
<b>2023</b>						
No	*	-	*	-	-	-
Yes	-	-	-	-	-	-

**Risdiplam - Treatment duration defined as the time from initiation to last available administration date (months)**

<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	63 (16.9)	*	67.7 (3.5)	67 (3.2)	-	-
(Median, [LQ, UQ])	-	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	57.8 (2.5)	-	58.3 (1.4)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-

<b>2019</b>						
(Mean, SD)	41.2 (5.4)	*	42.9 (3.6)	*	-	-
(Median, [LQ, UQ])	-	*	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	28.9 (5.9)	28.5 (6.9)	29.1 (5.5)	*	-	-
(Median, [LQ, UQ])	-	-	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>2021</b>						
(Mean, SD)	22 (4.8)	22.3 (5.1)	22.2 (5.2)	21 (3)	-	*
(Median, [LQ, UQ])	-	-	-	-	-	*
(Missing, %)	-	-	-	-	-	-
<b>2022</b>						
(Mean, SD)	11.5 (3.1)	10.5 (4.2)	12 (3)	11.4 (2.4)	*	*
(Median, [LQ, UQ])	-	-	-	-	*	*
(Missing, %)	-	-	-	-	-	-
<b>2023</b>						
(Mean, SD)	*	*	*	*	-	-
(Median, [LQ, UQ])	*	*	*	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>Risdiplam - Ongoing risdiplam at their last reported dose (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
No	*	*	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2019</b>						
No	-	-	-	-	-	-
Yes	*	-	-	*	-	-
missing	-	-	-	-	-	-
<b>2020</b>						

No	-	-	-	-	-	-
Yes	*	*	-	*	-	-
missing	5 (71.4%)	*	*	-	-	-
<b>2021</b>						
No	10 (11.4%)	-	8 (13.6%)	*	-	-
Yes	69 (78.4%)	11 (100.0%)	43 (72.9%)	9 (75.0%)	-	*
missing	9 (10.2%)	-	8 (13.6%)	*	-	-
<b>2022</b>						
No	10 (6.2%)	*	5 (5.3%)	*	-	-
Yes	140 (87.5%)	24 (85.7%)	82 (87.2%)	33 (94.3%)	-	-
missing	10 (6.2%)	-	7 (7.4%)	*	-	-
<b>2023</b>						
No	*	*	-	*	-	-
Yes	150 (98.7%)	24 (96.0%)	72 (100.0%)	51 (98.1%)	*	*
missing	-	-	-	-	-	-
<b>Risdiplam - Treatment discontinuation (n, %)</b>						
<b>Before 2011</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	-	-	-	-	-	-
Yes	*	*	-	-	-	-
<b>2018</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	-	-	-	-	-	-
Yes	-	-	-	-	-	-
<b>2020</b>						
No	*	*	*	-	-	-
Yes	-	-	-	-	-	-
<b>2021</b>						
No	6 (54.5%)	*	5 (50.0%)	-	-	-
Yes	5 (45.5%)	-	5 (50.0%)	-	-	-
<b>2022</b>						
No	*	*	-	*	-	-
Yes	9 (81.8%)	*	5 (100.0%)	-	-	-
<b>2023</b>						
No	-	-	-	-	-	-
Yes	*	*	-	*	-	-



<b>Risdiplam - Reason for treatment discontinuation (n, %)</b>						
<b>Before 2011</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2011 - 2013</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2014 - 2016</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2017</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	*	*	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2018</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2019</b>						
Elective choice	-	-	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	-	-	-	-	-	-
<b>2020</b>						
Elective choice	*	*	-	-	-	-
Insufficient benefit	-	-	-	-	-	-

Loss of response	-	-	-	-	-	-
Side effects from drug	*	-	*	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	*	-	*	-	-	-
<b>2021</b>						
Elective choice	*	*	-	-	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	*	-	*	-	-	-
Side effects from drug	5 (45.5%)	-	5 (50.0%)	-	-	-
Side effects from procedure	*	-	*	-	-	-
missing	*	-	*	-	-	-
<b>2022</b>						
Elective choice	5 (45.5%)	*	-	*	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	*	-	*	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	*	*	*	-	-	-
<b>2023</b>						
Elective choice	*	-	-	*	-	-
Insufficient benefit	-	-	-	-	-	-
Loss of response	-	-	-	-	-	-
Side effects from drug	-	-	-	-	-	-
Side effects from procedure	-	-	-	-	-	-
missing	*	*	-	-	-	-
<b>Risdiplam - Treatment duration in patients with treatment discontinuation (months)</b>						
<b>Before 2011</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2011 - 2013</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2014 - 2016</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2017</b>						
(Mean, SD)	*	*	-	-	-	-
(Median, [LQ, UQ])	*	*	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2018</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-

<b>2019</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	-	-	-	-	-	-
<b>2020</b>						
(Mean, SD)	-	-	-	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	*	*	*	-	-	-
<b>2021</b>						
(Mean, SD)	4.2 (1.9)	-	4.2 (1.9)	-	-	-
(Median, [LQ, UQ])	-	-	-	-	-	-
(Missing, %)	6 (54.5%)	*	5 (50.0%)	-	-	-
<b>2022</b>						
(Mean, SD)	11 (7.3)	*	14.8 (4.9)	-	-	-
(Median, [LQ, UQ])	-	*	-	-	-	-
(Missing, %)	*	*	-	*	-	-
<b>2023</b>						
(Mean, SD)	*	*	-	*	-	-
(Median, [LQ, UQ])	*	*	-	*	-	-
(Missing, %)	-	-	-	-	-	-
<b>Treated - At least one SAE reported in the registry related to any DMT (n, %)</b>						
<b>Before 2011</b>						
No	32 (100.0%)	*	22 (100.0%)	8 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	47 (100.0%)	7 (100.0%)	28 (100.0%)	10 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	92 (100.0%)	15 (100.0%)	59 (100.0%)	18 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	96 (100.0%)	42 (100.0%)	35 (100.0%)	19 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	236 (99.6%)	64 (98.5%)	113 (100.0%)	58 (100.0%)	-	-
Yes	*	*	-	-	-	-
<b>2019</b>						
No	350 (100.0%)	95 (100.0%)	162 (100.0%)	91 (100.0%)	*	*
Yes	-	-	-	-	-	-
<b>2020</b>						
No	478 (99.8%)	130 (100.0%)	197 (100.0%)	151 (99.3%)	-	-
Yes	*	-	-	*	-	-
<b>2021</b>						
No	539 (100.0%)	156 (100.0%)	227 (100.0%)	153 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2022</b>						

No	321 (100.0%)	90 (100.0%)	130 (100.0%)	96 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2023</b>						
No	187 (98.9%)	60 (100.0%)	72 (97.3%)	54 (100.0%)	-	-
Yes	*	-	*	-	-	-

**Nusinersen - At least one SAE reported in the registry related to nusinersen (n, %)**

<b>Before 2011</b>						
No	25 (100.0%)	-	17 (100.0%)	7 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	41 (100.0%)	7 (100.0%)	23 (100.0%)	9 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	83 (100.0%)	15 (100.0%)	52 (100.0%)	16 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	84 (100.0%)	39 (100.0%)	28 (100.0%)	17 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	209 (99.5%)	60 (98.4%)	95 (100.0%)	54 (100.0%)	-	-
Yes	*	*	-	-	-	-
<b>2019</b>						
No	318 (100.0%)	89 (100.0%)	143 (100.0%)	85 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2020</b>						
No	439 (99.8%)	125 (100.0%)	174 (100.0%)	140 (99.3%)	-	-
Yes	*	-	-	*	-	-
<b>2021</b>						
No	473 (100.0%)	144 (100.0%)	186 (100.0%)	141 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2022</b>						
No	251 (100.0%)	71 (100.0%)	96 (100.0%)	81 (100.0%)	*	-
Yes	-	-	-	-	-	-
<b>2023</b>						
No	171 (100.0%)	57 (100.0%)	63 (100.0%)	50 (100.0%)	-	-
Yes	-	-	-	-	-	-

**Zolgensma - At least one SAE reported in the registry related to onasemnogene abeparvovec-xioi (n, %)**

<b>Before 2011</b>						
No	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	-	-	-	-	-	-
<b>2017</b>						
No	-	-	-	-	-	-
<b>2018</b>						

No	5 (100.0%)	*	*	-	-	-
<b>2019</b>						
No	23 (100.0%)	17 (100.0%)	5 (100.0%)	-	-	*
<b>2020</b>						
No	41 (100.0%)	28 (100.0%)	10 (100.0%)	*	-	-
<b>2021</b>						
No	73 (100.0%)	53 (100.0%)	14 (100.0%)	5 (100.0%)	-	-
<b>2022</b>						
No	45 (100.0%)	29 (100.0%)	10 (100.0%)	*	-	-
<b>2023</b>						
No	11 (100.0%)	9 (100.0%)	*	-	-	-
<b>Risdiplam - At least one SAE reported in the registry related to risdiplam (n, %)</b>						
<b>Before 2011</b>						
No	17 (100.0%)	*	13 (100.0%)	*	-	-
Yes	-	-	-	-	-	-
<b>2011 - 2013</b>						
No	30 (100.0%)	7 (100.0%)	17 (100.0%)	6 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2014 - 2016</b>						
No	60 (100.0%)	11 (100.0%)	40 (100.0%)	9 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2017</b>						
No	68 (100.0%)	35 (100.0%)	20 (100.0%)	13 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2018</b>						
No	149 (100.0%)	44 (100.0%)	73 (100.0%)	31 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2019</b>						
No	195 (100.0%)	45 (100.0%)	101 (100.0%)	49 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2020</b>						
No	263 (100.0%)	68 (100.0%)	116 (100.0%)	79 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2021</b>						
No	281 (100.0%)	76 (100.0%)	134 (100.0%)	69 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2022</b>						
No	140 (100.0%)	47 (100.0%)	70 (100.0%)	21 (100.0%)	-	-
Yes	-	-	-	-	-	-
<b>2023</b>						
No	104 (98.1%)	37 (100.0%)	39 (95.1%)	28 (100.0%)	-	-
Yes	*	-	*	-	-	-
<b>Treated - Incidence rate of listed SAESI (per patient-year)</b>						
<b>Before 2011</b>	-	-	-	-	-	*
<b>2011 - 2013</b>	-	-	-	-	-	*
<b>2014 - 2016</b>	0	0	0	0	-	*

<b>2017</b>	0	0	0	0	-	*
<b>2018</b>	0	0	0	0	0	*
<b>2019</b>	0	0	0	0	0	*
<b>2020</b>	0	0	0	0	0	*
<b>2021</b>	0	0	0	0	0	*
<b>2022</b>	0	0	0	0	0	*
<b>2023</b>	0	0	0	0	0	*



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