## Appendix 10. Impact and views Type 4 summary

	А	В	С	D	E	F	G	Н	Ι	J	К
1	Q1. Respondent's age.										
2	Answer Choices	Respor	nses								
3	36 - 45 years	33.3%	1								
4	46 - 55 years	33.3%	1								
5	56 - 65 years	33.3%	1								
6		Total	3								
7											
8											
9	Q2. Who is their main unpaid carer / unpaid personal assistant										
10											
11	Answer Choices	Respor	nses								
-	My partner	66.7%	2								
13	I don't have any unpaid carers / unpaid personal assistants	33.3%	1								
14		Answers	3								
15											-
	Q3. Are the interventions and support the person with SMA and the	eir carer/	PA ha	ve in the	eir day	-to-day l	ite en	ough for	the peros	n with SMA	to
-	manage and		[								
17											
18		Yes		Not really		No		No/not really		Not applicable	
-	Keep physically well	33.3%	1	66.7%	2	0.0%	0	66.7	2	0.0%	0
_	Get enough sleep	33.3%	1	66.7%	2	0.0%	0	66.7	2	0.0%	0
_	Manage financially	33.3%	1	66.7%	2	0.0%	0	66.7	2	0.0%	0
-	Work / study for the hours you wish	0.0%	0	33.3%	1	33.3%	1	66.7	2	33.3%	1
_	Keep emotionally well	66.7%	2	33.3%	1	0.0%	0	33.3	1	0.0%	0
_	Get out and about	66.7%	2	33.3%	1	0.0%	0	33.3	1	0.0%	0
-	Keep socially connected	66.7%	2	33.3%	1	0.0%	0	33.3	1	0.0%	0
26									Answers	3	
27											

## Appendix 10. Impact and views Type 4 summary

	Α	В	С	D	E	F	G	Н	Ι	J	K	
	Q4. Are the interventions and support the person with SMA and their carer/PA have in their day-to-day life enough for the unpaid carer(s) to manage											
28	28 and											
29		Yes		Not re	eally	No		No/not really		Not applicable		
30	Get enough sleep	0.0%	0	33.3%	1	0.0%	0	33.3	1	66.7%	2	
31	Keep emotionally well	33.3%	1	33.3%	1	0.0%	0	33.3	1	33.3%	1	
32	Keep physically well	66.7%	2	0.0%	0	0.0%	0	0.0	0	33.3%	1	
33	Get out and about	66.7%	2	0.0%	0	0.0%	0	0.0	0	33.3%	1	
34	Keep socially connected	66.7%	2	0.0%	0	0.0%	0	0.0	0	33.3%	1	
35	Manage financially	33.3%	1	0.0%	0	0.0%	0	0.0	0	66.7%	2	
36	Work /study for the hours they wish	33.3%	1	0.0%	0	0.0%	0	0.0	0	66.7%	2	
37								Answers		3		
38												
39	Q5. What the respondent knows about the treatment nusinersen											
40		Know a	(now a lot		2		Know a bit		4		Don't know anything	
41			Nos.		Nos.		Nos.		Nos.		Nos	
42		0.00%	0	66.7%	2	33.3%	1	0.0%	0	0.00%	0	
43												
44	Q6. Do you want to have the opportunity to access nusinersen?											
45	Answer Choices	Respor	nses									
46	Yes	66.7%	2									
47	Don't know	33.3%	1									
48		Answers	3									
49												
50	50 Q7. What, if anything, do you believe nusinersen would do for you (tick as many as apply)											
51	Answer Choices	Responses										
52	It will improve my muscle strength	100.0%	3									
53	It will maintain my muscle strength	100.0%	3									
54	It will extend the life expectation that is associated with my type of S	33.3%	1									
55	Other	33.3%	1									

## Appendix 10. Impact and views Type 4 summary

	Α	В	С	D	E	F	G	Н	Ι	J	К
56	Q8. if it is clinically safe for someone should they be given the oppo	ortunity?									
57	Answer Choices	Respor	nses								
58	Yes	100.0%	3								
59		Total	3								
60											
61											
62	Answer Choices	Respor	nses								
63	SMA Type 1	100.0%	3								
64	SMA Type 1 / 2	100.0%	3								
65	SMA Type 2	100.0%	3								
66	SMA Type 2 / 3	100.0%	3								
67	SMA Type 3	100.0%	3								
68	SMA Type 4	100.0%	3								
69	age 0 - 35 months	100.0%	3								
70	age 3 - 7 years	100.0%	3								
71	age 8 - 12 years	100.0%	3								
72	age 13 - 17 years	100.0%	3								
73	age 18 - 25 years	100.0%	3								
74	age 26 years +	100.0%	3								
75	Don't know	33.3%	1								
76		Answers	3								
77											
78	Type 4 age 46-55 years partner										
	The biggest challenges are lack of mobility and very low levels of energy and the affect this has on both our lives physically and emotionally. Everyday activities such as getting showered and dressed, preparing food and travelling all require assistance and take a lot of effort. My										
	partner (with SMA) cannot manage these simple everyday activities v	without h	elp and	d is exh	austed	upon co	mpleti	on. This a	ffects him	n	
79	emotionally too as he feels he cannot contribute equally in the upbri	nging of c	our chi	dren ar	nd looki	ing after	our he	ome.			