	А	В	С	D	E	F	G	Н				
1	1. Respondents giving their views	Number										
2	People with SMA	56			Note: due to availability of nusinersen via the Type 1							
3	Main unpaid carers	55			Expanded Access Programme, only 8.6% of views were							
4	Other relatives	21			from those affected by Type 1. This condition affects							
5	Bereaved by SMA	5			some 60% of those born with SMA.							
6	Parent of child treated with nusinersen	14										
7	Total	151										
8												
9	2. How respondents rate their knowledge of the treatn	nent										
10												
11	Scale	1	2	3	4	5						
						Don't						
		Know a		Know a		know						
12		lot		bit		anything	Total					
13	People with SMA	15	9	21	3	8	56					
14	Main unpaid carers	18	12	21	1	3	55					
15	Other relatives	4	2	11	2	2	21					
16	Bereaved by SMA	0	0	2	2	1	5					
17	Total	37	23	55	8	14	137					
18	%	27	17	40	6	10	100					
19												
20	3. What respondents believe nusinersen will do for the	em as a pe		SMA / th	eir relative	with SMA	1					
			with	main								
21			SMA	carer	relative	Total	%					
	Will maintain muscle strength		44	43	14	101	77					
	Will improve muscle strength		37 25	44	15	96	73					
_	Will extend the life expectation associated with this type of SMA			31	7	63	48					
_	Other			10	7	36	27					
	Unlikely to change the natural course of their condition		6	2	1	9	7					
27			56	55	21	132						

	A	В	С	D	E	F	G	Н				
28	4. Do you as a person with SMA want/ do you want your relative with SMA to have the opportunity to access nusinersen?											
29												
				Don't								
30		Yes	No	Know	Total							
31	People with SMA	46	6	4	56							
32	Main Carer	52	0	3	55							
33	Other relative	4	3	1	8							
34	Total	102	9	8	119							
35	%	86	8	7	100							
36												

	A	В	С	D	E	F	G	Н
37	4. Concerns people have that they have read about or	_	_				J	
38	The content of people mate may make read about or							
-	Responses from:	Nos.	%					
	Those with SMA	31	42					
	Main carers	32	43					
42	Other relatives	11	15					
43		74	100					
44	Concern expressed:	Nos.	%					
45	No	35	47					
46	Lumbar puncture process / safety	10	14					
47	Headaches / nausea	6	8					
48	Price	6	8					
49	Scoliosis / spinal fusion may prevent treatment	5	7					
50	Risk of respiratory issues / chest infection	4	5					
51	Side effects	4	5					
52	Unknown long term outcomes	4	5					
53	Not really	3	4					
54	Discomfort of process	3	4					
55	No guarantee it will work	2	3					
	Frequency of treatment / scheduling	2	3					
57	Constipation	1	1					
58	Won't help due to age	1	1					
59	Injection	1	1					
	Necessary physio and other follow up care may not be							
	there	1	1					
_	Paralysis	1	1					
	Impact on kidney function	1	1					
	Low bone density may mean not possible	1	1					
	Long term impact of repeated lumbar punctures	1	1					
65	Effects wearing of more quickly if older	1	1					

	А	В	С	D	E	F	G	Н			
66	5. If it is clinically safe for someone with 5q SMA to be treated with nusinersen, should they be given the opportunity to do so?										
67											
				Don't							
68		Yes	No	Know	Total						
69	People with SMA	52	0	4	56						
70	Main unpaid carers	51	0	4	55						
71	Other relatives	19	0	2	21						
72	Bereaved by SMA	3	0	2	5						
73	Parent of child treated with nusinersen	13	0	1	14						
74	Total	138	0	13	151						
75	%	91	0	9	100						
76											

	A	В	С	D	E	F	G	Н
77	6. 'Groups' that respondents think might benefit more	at apply)						
78								
								Total who consider this
		with	main					group might respond more
79	SMA Type that might respond more:	SMA	carer	relative	bereaved	treated	Number	%
80	SMA Type 1	28	29	11	2	10	80	53
81	SMA Type 1 / 2	29	32	11	1	10	83	55
82	SMA Type 2	33	34	11	1	10	89	59
83	SMA Type 2 / 3	28	28	9	1	8	74	49
84	SMA Type 3	29	23	6	1	6	65	43
85	SMA Type 4	18	20	4	1	5	48	32
86	Age of person that might respond more:							
87	age 0 - 35 months	27	32	10	2	7	78	52
88	age 3 - 7 years	24	31	10	1	6	72	48
89	age 8 - 12 years	24	28	8	1	6	67	44
90	age 13 - 17 years	21	25	6	1	6	59	39
91	age 18 - 25 years	22	22	5	1	6	56	37
92	age 26 years+	20	22	5	1	5	53	35
93	other	9	13	9	1	2	34	23
94	don't know	18	9	6	2	3	38	25
95	Total answered	56	55	21	5	14	151	
96		_						_

	А	В	С	D	Е	F	G	Н
		with	main					
97	6a. These respondents are affected by:	SMA	carer	relative	bereaved	treated	Total	%
98	Type 1	1	0	0	4	8	13	8.6
99	Type 1/2	2	3	0	1	4	10	6.6
100	Type 2	23	32	13	0	1	69	45.7
101	Type 2/3	6	1	2	0		9	6.0
102	Type 3	24	19	6	0	1	50	33.1
103	Type 4	0	0	0	0		0	0.0
104		56	55	21	5	14	151	100.0
		with	main					
105	6b. Age of person they are / are related to	SMA	carer	relative	bereaved	treated	Total	%
106	0 - 2 years	3	7	4		5	19	13
107	3 - 4 years	1	6	2		3	12	8
108	5 - 12 years	2	18	7		4	31	22
109	13 - 17 years	9	4	4		0	17	12
110	18 - 25 years	10	9	1		0	20	14
111	26 - 35 years	9	4	0		0	13	9
112	26 - 45 years	6	3	2		0	11	8
113	46 - 55 years	9	1	1		0	11	8
114	56 - 65 years	3	2	0		0	5	3
115	66 + years	4	1	0		0	5	3
116		56	55	21		12	144	100.0