

Appendix 6. Survey Jan - Feb 2018/Scottish survey Dec - Jan 2018:

Parents / carers of those treated with nusinersen

	A	B	C	D	E	F
1	1. Respondents					
2						
3		England survey	Scotland survey	Total respondents		
4		Nos	Nos.	Nos	%	
5	Parent / main carer of a child currently being treated	20	7	27	93	
6	Parent / main carer of a child who was treated	2		2	7	
7		22	7	29		
8						
9	2. Type of 5q SMA affecting / that affected their child					
10						
11		England survey	Scotland survey	Total respondents		
12		Nos	Nos.	Nos	%	
13	Type 1	14	5	19	66	
14	Type 1 / 2	5	4	9	31	
15	Type 2	2		2	7	
16	Type 3	1	0	1	3	
17		22	9	31		
18						

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19	3. How old their child was when treatment started					
20						
21		England survey	Scotland survey	Total respondents		
22		Nos	Nos.	Nos	%	
23	< 7 months	3	2	5	17	
24	8 - 12 months	5	2	7	24	
25	13 - 24 months	6	1	7	24	
26	25 - 36 months	2	1	3	10	
27	37 months +	5		5	17	
28	9 years+	1	1	2	7	
29		22	7	29		
30						
31	4. If bereaved by the loss of their child					
32						
33		England survey	Scotland survey	Total respondents		
34		Nos	Nos.	Nos	%	
35	No	20	7	27	93	
36	Yes	2	0	2	7	
37		22	7	29		
38						
39						
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45						
46						

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	A	B	C	D	E	F
47	Respondents with children still being treated:					
48	5. How many nusinersen injections their child had had as of 31st January 2018 (England)	Scottish survey 31/		Total		
49						
50		England survey	Scotland survey	Total respondents		
51		Nos	Nos.	Nos	%	
52	0 - 4 injections	3	5	8	30	
53	5 - 7 injections	16	2	18	67	
54	11+ injections	1	0	1	4	
55		20	7	27		
56						
57	Bereaved respondents only:					
58	6. How many injections their child had					
59		Number				
60	0 - 4 injections	1				
61	5 - 7 injections	1				
62		2				
63						

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64	All respondents:					
65	7. Aspects reported in open comments about the impact of treatment on child / young person					
66						
67		Number of injections				
68	Total of 20 respondents made comments	0 to 4	5 to 7	11+	Total	%
69	Physical / muscle improvements	4	13	2	19	95
70	Much happier		7	1	8	40
71	Respiratory gains	1	5	1	7	35
72	General improvement in health	1	2	1	4	20
73	Increased vocalisation		2		2	10
74	Tolerates procedure well		2		2	10
75	No physical / muscle improvement	1			1	5
76	No respiratory gain		1		1	5
77	Improved swallow		1		1	5
78	Improved quality of life		1		1	5
79	Emotionally dislikes procedure		1		1	5
80						
81						
82	8. Aspects reported in open comments about the impact of treatment on family					
83						
84		Number of injections				
85	Total of 20 respondents made comments	0 to 4	5 to 7	11+	Total	%
86	Given hope	2	10	1	13	65
87	Emotionally positive / happier	1	7		8	40
88	Decrease in care needed	2	1	1	4	20
89	Stressful attending treatment	1	1		2	10
90	More inclusive family time		1		1	5
91	More relaxed		1		1	5
92	Stressed as expectations not met	1			1	5
93						

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94	9. Aspects reported in open comments about expectations /(hope) of treatment					
95						
96		Number of injections				
97	Total of 20 respondents made comments	0 to 4	5 to 7	11+	Total	%
98	Ongoing physical/muscle improvements	1	3	1	5	25
99	Slow and steady /gradual gains	1	3		4	20
100	Improved respiratory		3		3	15
101	Walk and live normal life		2	1	3	15
102	Improved swallow		2		2	10
103	Stability / no deterioration		2		2	10
104	Improved strength		2		2	10
105	Increased independence / less care (health and social)		1	1	2	10
106	Improvement with long term exposure	1			1	5
107	Better life expectancy		1		1	5