

Appendix 8. Surveys Jan - Feb 2018

Summary of All Views about access to nusinersen

	A	B	C	D	E	F	G	H
1	1. Respondents giving their views	Number						
2	People with SMA	56			Note: due to availability of nusinersen via the Type 1 Expanded Access Programme, only 8.6% of views were from those affected by Type 1. This condition affects some 60% of those born with SMA.			
3	Main unpaid carers	55						
4	Other relatives	21						
5	Bereaved by SMA	5						
6	Parent of child treated with nusinersen	14						
7	Total	151						
8								
9	2. How respondents rate their knowledge of the treatment							
10								
11	Scale	1	2	3	4	5		
12		Know a lot		Know a bit		Don't know 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 them as a person with SMA / their relative with SMA							
21			with SMA	main carer	relative	Total	%	
22	Will maintain muscle strength		44	43	14	101	77	
23	Will improve muscle strength		37	44	15	96	73	
24	Will extend the life expectation associated with this type of SMA		25	31	7	63	48	
25	Other		19	10	7	36	27	
26	Unlikely to change the natural course of their condition		6	2	1	9	7	
27			56	55	21	132		

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37	4. Concerns people have that they have read about or heard about - reported in open comments							
38								
39	Responses from:	Nos.	%					
40	Those with SMA	31	42					
41	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					
56	Frequency of treatment / scheduling	2	3					
57	Constipation	1	1					
58	Won't help due to age	1	1					
59	Injection	1	1					
60	Necessary physio and other follow up care may not be there	1	1					
61	Paralysis	1	1					
62	Impact on kidney function	1	1					
63	Low bone density may mean not possible	1	1					
64	Long term impact of repeated lumbar punctures	1	1					
65	Effects wearing of more quickly if older	1	1					

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97	6a. These respondents are affected by:	with SMA	main 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
105	6b. Age of person they are / are related to	with SMA	main 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