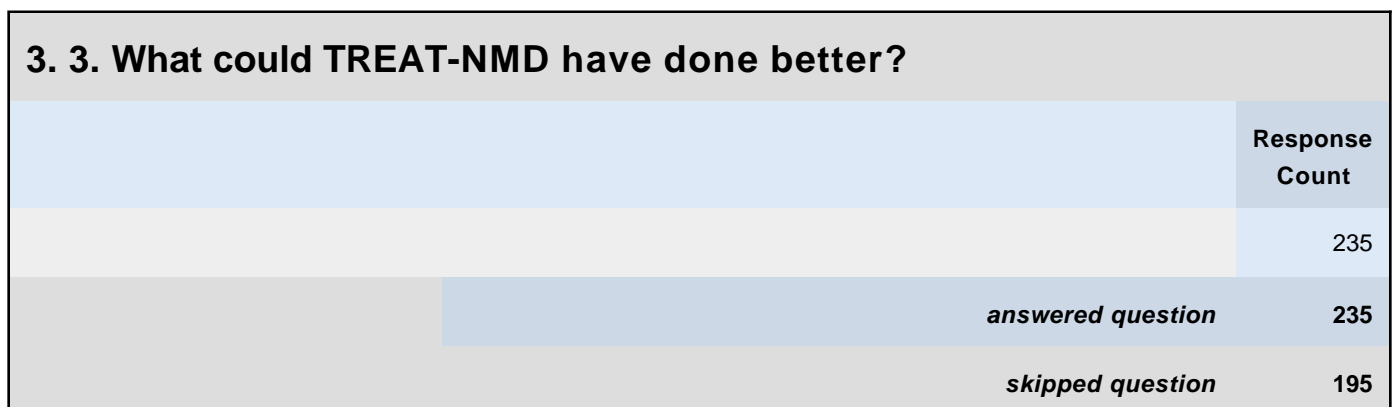
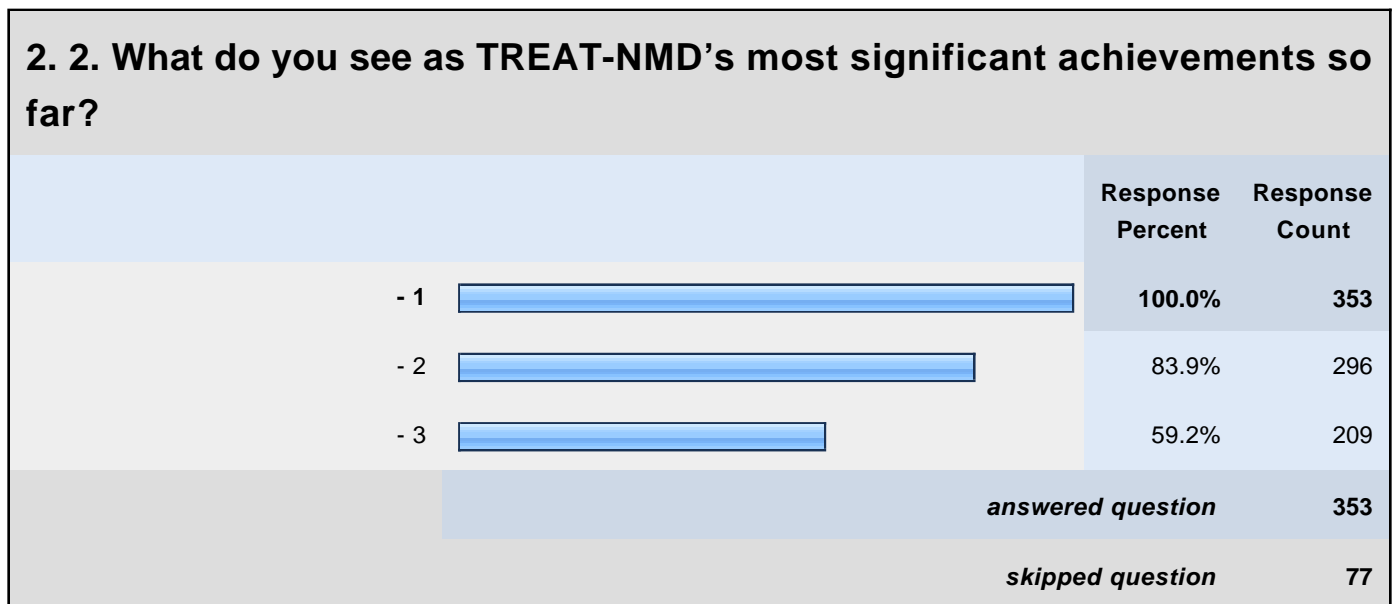
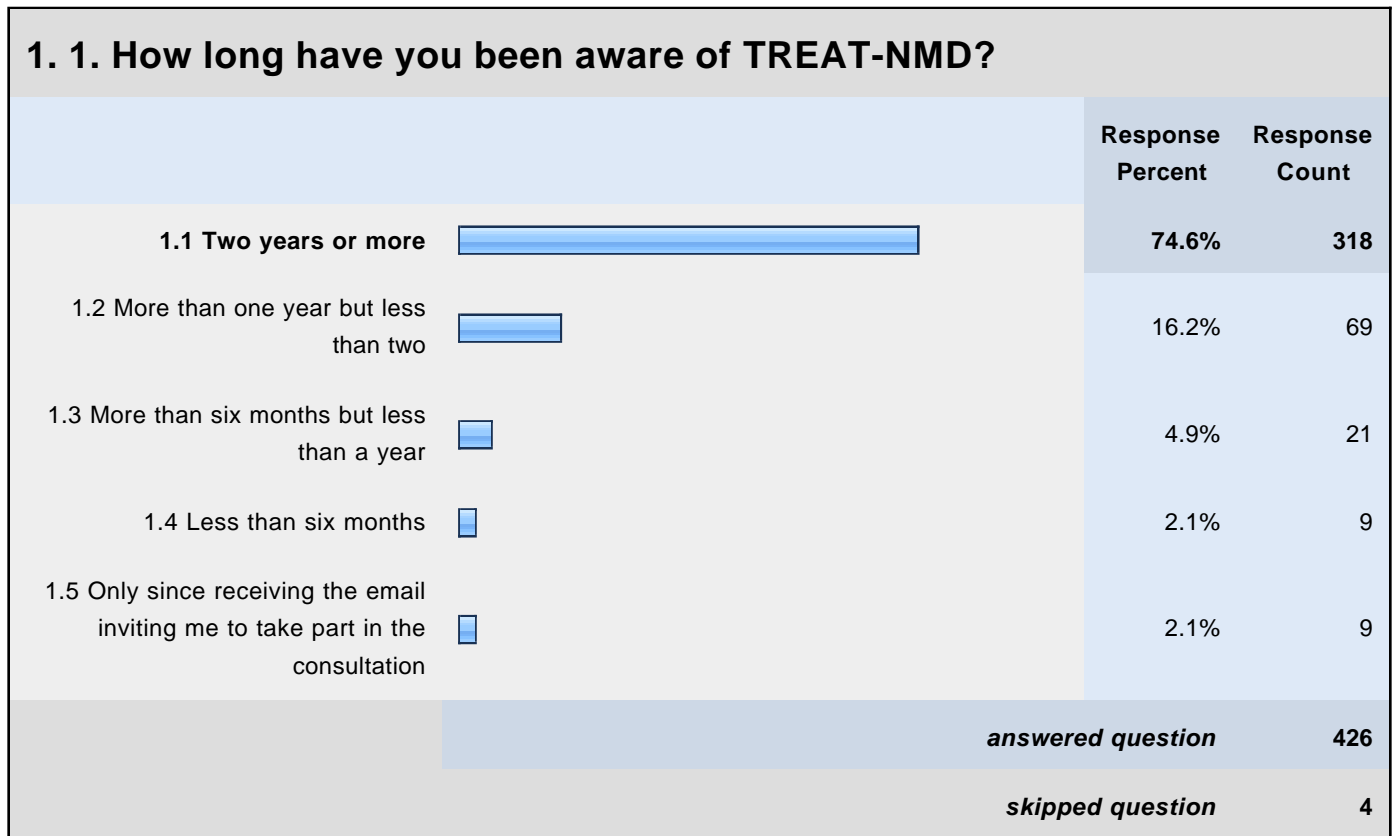


## The future of TREAT-NMD: Consultation Questions



#### 4. 4. What do you see as the main obstacles to TREAT-NMD's continuation in the future?

	Response Count
	287
<i>answered question</i>	287
<i>skipped question</i>	143

#### 5.

##### 5.1

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Facilitating international collaborations between research groups to share data and experience and develop harmonized tools and protocols.	91.3% (337)	7.3% (27)	0.8% (3)	0.5% (2)	369
	<i>answered question</i>				369
	<i>skipped question</i>				61

6.

5.1.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		75.0%	6
Too expensive		0.0%	0
Duplicates work done elsewhere		25.0%	2
Other (please specify)		0.0%	0
<b>answered question</b>			<b>8</b>
<b>skipped question</b>			<b>422</b>



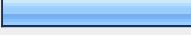
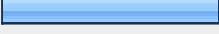
7.

5.2

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Evaluating existing animal models for NMDs, developing international consensus on their use and creating standard operating procedures (SOPs) to allow standardized assessment across labs <a href="http://www.treat-nmd.eu/animalmodels">www.treat-nmd.eu/animalmodels</a>	42.8% (158)	<b>48.8% (180)</b>	3.8% (14)	4.6% (17)	369
<b>answered question</b>					<b>369</b>
<b>skipped question</b>					<b>61</b>

8.

5.2.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		30.4%	7
Too expensive		4.3%	1
Duplicates work done elsewhere		30.4%	7
Other (please specify)		34.8%	8
<i>answered question</i>			<b>23</b>
<i>skipped question</i>			<b>407</b>



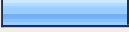
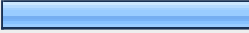
9.

5.3

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Facilitating global exchange of biomaterials for research via an online database of DNA, cell and tissue samples (EuroBioBank) <a href="http://www.treat-nmd.eu/eurobiobank">www.treat-nmd.eu/eurobiobank</a>	58.6% (215)	34.1% (125)	2.2% (8)	5.2% (19)	367
<i>answered question</i>					<b>367</b>
<i>skipped question</i>					<b>63</b>

10.

5.3.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		33.3%	5
Too expensive		6.7%	1
Duplicates work done elsewhere		20.0%	3
Other (please specify)		40.0%	6
			<b>answered question</b>
			<b>15</b>
			<b>skipped question</b>
			<b>415</b>



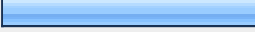
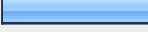
11.

5.4

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Acting as a platform for spin-off projects (bringing participants together in the set-up phase, assisting in proposal-writing, and acting as a communication and dissemination platform).	47.8% (175)	41.8% (153)	4.6% (17)	5.7% (21)	366
					<b>answered question</b>
					<b>366</b>
					<b>skipped question</b>
					<b>64</b>

## 12.

### 5.4.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		29.4%	5
Too expensive		5.9%	1
<b>Duplicates work done elsewhere</b>		<b>41.2%</b>	<b>7</b>
Other (please specify)		23.5%	4
<b>answered question</b>			<b>17</b>
<b>skipped question</b>			<b>413</b>



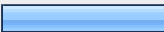
## 13.

### 5.5

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing expert evaluation and advice to researchers on the steps to be taken to take promising drugs and therapeutic targets through to clinical trial (TREAT-NMD Advisory Committee for Therapeutics, TACT) <a href="http://www.treat-nmd.eu/TACT">www.treat-nmd.eu/TACT</a>	<b>69.4% (249)</b>	24.2% (87)	4.7% (17)	1.7% (6)	359
<b>answered question</b>					<b>359</b>
<b>skipped question</b>					<b>71</b>

14.

5.5.1 If you selected “activity should not continue”, please give your reason:

	Response Percent	Response Count
Work has already been achieved 	10.5%	2
Too expensive	0.0%	0
<b>Duplicates work done elsewhere</b> 	<b>63.2%</b>	<b>12</b>
Other (please specify) 	26.3%	5
<i>answered question</i>		<b>19</b>
<i>skipped question</i>		<b>411</b>



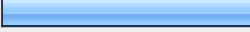
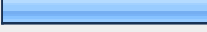
15.

5.6

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing expert support services for neuromuscular clinical trials, advising researchers, companies or CROs (Clinical Trial Coordination Centre, CTCC) <a href="http://www.treat-nmd.eu/ctcc">www.treat-nmd.eu/ctcc</a>	<b>69.1% (246)</b>	26.4% (94)	2.5% (9)	2.0% (7)	356
<i>answered question</i>					<b>356</b>
<i>skipped question</i>					<b>74</b>

16.

5.6.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		13.3%	2
Too expensive		13.3%	2
<b>Duplicates work done elsewhere</b>		<b>40.0%</b>	<b>6</b>
Other (please specify)		33.3%	5
<i>answered question</i>			<b>15</b>
<i>skipped question</i>			<b>415</b>

17.

5.7

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing a global registry of care and trial sites specializing in NMDs including information about their facilities (Care and Trial Site Registry, CTSR) <a href="http://www.treat-nmd.eu/ctsr">www.treat-nmd.eu/ctsr</a>	<b>67.6% (238)</b>	28.1% (99)	3.1% (11)	1.1% (4)	352
<i>answered question</i>					<b>352</b>
<i>skipped question</i>					<b>78</b>

18.

5.7.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		26.7%	4
Too expensive		6.7%	1
<b>Duplicates work done elsewhere</b>		<b>46.7%</b>	<b>7</b>
Other (please specify)		20.0%	3
			<b>answered question</b>
			<b>15</b>
			<b>skipped question</b>
			<b>415</b>


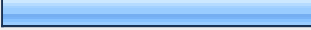

19.

5.8

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing patient registries to facilitate patient recruitment for trials and provide feedback to patients on developments relevant to their condition <a href="http://www.treat-nmd.eu/patientregistries">www.treat-nmd.eu/patientregistries</a>	<b>76.7% (277)</b>	19.7% (71)	1.7% (6)	1.9% (7)	361
					<b>answered question</b>
					<b>361</b>
					<b>skipped question</b>
					<b>69</b>

20.

5.8.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		16.7%	2
Too expensive		0.0%	0
Duplicates work done elsewhere		50.0%	6
Other (please specify)		33.3%	4
<i>answered question</i>			12
<i>skipped question</i>			418

21.

5.9

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing and validating outcome measures appropriate for clinical trials in different conditions <a href="http://www.treat-nmd.eu/outcome-measures">www.treat-nmd.eu/outcome-measures</a>	69.1% (248)	25.3% (91)	2.2% (8)	3.3% (12)	359
<i>answered question</i>					359
<i>skipped question</i>					71

22.

5.9.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		23.1%	3
Too expensive		15.4%	2
Duplicates work done elsewhere		15.4%	2
Other (please specify)		46.2%	6
<i>answered question</i>			<b>13</b>
<i>skipped question</i>			<b>417</b>



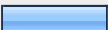
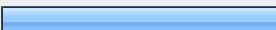
23.

5.10

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing an online Registry of Outcome Measures with active user input to facilitate access to existing measures <a href="http://www.treat-nmd.eu/rom">www.treat-nmd.eu/rom</a>	49.6% (177)	41.2% (147)	3.4% (12)	5.9% (21)	357
<i>answered question</i>					<b>357</b>
<i>skipped question</i>					<b>73</b>

24.

5.10.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		27.8%	5
Too expensive		11.1%	2
Duplicates work done elsewhere		16.7%	3
Other (please specify)		44.4%	8
<i>answered question</i>			<b>18</b>
<i>skipped question</i>			<b>412</b>

25.

5.11

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Engaging the regulatory authorities, such as EMA and FDA, in strategic dialogue on areas of key concern to NMDs.	<b>59.9% (212)</b>	31.4% (111)	2.8% (10)	5.9% (21)	354
<i>answered question</i>					<b>354</b>
<i>skipped question</i>					<b>76</b>

26.

5.11.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		21.4%	3
Too expensive		7.1%	1
Duplicates work done elsewhere		28.6%	4
Other (please specify)		42.9%	6
<i>answered question</i>			14
<i>skipped question</i>			416



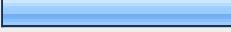
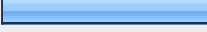
27.

5.12

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Maintaining a database of regulatory requirements for clinical trials in different countries <a href="http://www.treat-nmd.eu/regulatoryaffairs">www.treat-nmd.eu/regulatoryaffairs</a>	43.1% (153)	43.1% (153)	7.3% (26)	6.5% (23)	355
<i>answered question</i>					355
<i>skipped question</i>					75

28.

5.12.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		14.8%	4
Too expensive		14.8%	4
<b>Duplicates work done elsewhere</b>		<b>37.0%</b>	<b>10</b>
Other (please specify)		33.3%	9
<i>answered question</i>			<b>27</b>
<i>skipped question</i>			<b>403</b>





29.

5.13

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Supporting national networking of expert centres and patient organizations in countries worldwide with the aim of improving care standards and facilitating trial-readiness	<b>69.2% (247)</b>	26.1% (93)	2.8% (10)	2.0% (7)	357
<i>answered question</i>					<b>357</b>
<i>skipped question</i>					<b>73</b>

30.

5.13.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		16.7%	2
Too expensive		16.7%	2
<b>Duplicates work done elsewhere</b>		<b>41.7%</b>	<b>5</b>
Other (please specify)		25.0%	3
<i>answered question</i>			<b>12</b>
<i>skipped question</i>			<b>418</b>



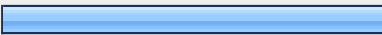
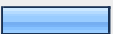
31.

5.14

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Undertaking and updating systematic reviews of published and unpublished clinical trials (Cochrane reviews).	43.0% (153)	<b>43.5% (155)</b>	7.3% (26)	6.2% (22)	356
<i>answered question</i>					<b>356</b>
<i>skipped question</i>					<b>74</b>

32.

5.14.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		6.9%	2
Too expensive		13.8%	4
<b>Duplicates work done elsewhere</b>		<b>62.1%</b>	<b>18</b>
Other (please specify)		17.2%	5
<i>answered question</i>			<b>29</b>
<i>skipped question</i>			<b>401</b>

33.

5.15

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing and implementing international consensus guidelines on standards of care for NMDs <a href="http://www.treat-nmd.eu/care">www.treat-nmd.eu/care</a>	<b>69.6% (250)</b>	24.0% (86)	4.7% (17)	1.7% (6)	359
<i>answered question</i>					<b>359</b>
<i>skipped question</i>					<b>71</b>

34.

5.15.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		16.7%	4
Too expensive		12.5%	3
Duplicates work done elsewhere		29.2%	7
Other (please specify)		41.7%	10
			<b>answered question</b>
			<b>24</b>
			<b>skipped question</b>
			<b>406</b>



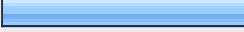
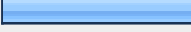
35.

5.16

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing and implementing international consensus guidelines on diagnostic standards and techniques for NMDs <a href="http://www.treat-nmd.eu/diagnosis">www.treat-nmd.eu/diagnosis</a>	63.4% (227)	30.2% (108)	4.7% (17)	1.7% (6)	358
					<b>answered question</b>
					<b>358</b>
					<b>skipped question</b>
					<b>72</b>

36.

5.16.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		26.1%	6
Too expensive		4.3%	1
<b>Duplicates work done elsewhere</b>		<b>39.1%</b>	<b>9</b>
Other (please specify)		30.4%	7
<i>answered question</i>			<b>23</b>
<i>skipped question</i>			<b>407</b>



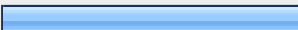
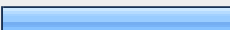
37.

5.17

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Support lobbying initiatives (providing expert opinions and information on best practice to influence national healthcare and research decisions).	<b>43.1% (155)</b>	<b>43.1% (155)</b>	6.9% (25)	6.9% (25)	360
<i>answered question</i>					<b>360</b>
<i>skipped question</i>					<b>70</b>

38.

5.17.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		7.4%	2
Too expensive		7.4%	2
<b>Duplicates work done elsewhere</b>		<b>48.1%</b>	<b>13</b>
Other (please specify)		37.0%	10
<i>answered question</i>			<b>27</b>
<i>skipped question</i>			<b>403</b>

39.

5.18

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Hosting small focused workshops on a particular area where progress is required.	<b>45.7% (163)</b>	43.4% (155)	8.1% (29)	2.8% (10)	357
<i>answered question</i>					<b>357</b>
<i>skipped question</i>					<b>73</b>

40.

5.18.1 If you selected “activity should not continue”, please give your reason:

	Response Percent	Response Count
Work has already been achieved	2.9%	1
Too expensive	11.8%	4
<b>Duplicates work done elsewhere</b>	<b>61.8%</b>	<b>21</b>
Other (please specify)	23.5%	8
<i>answered question</i>		<b>34</b>
<i>skipped question</i>		<b>396</b>


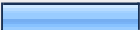
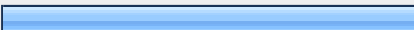

41.

5.19

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Hosting larger international conferences on broader issues in translational research in NMDs.	34.0% (121)	<b>52.0% (185)</b>	10.1% (36)	3.9% (14)	356
<i>answered question</i>					<b>356</b>
<i>skipped question</i>					<b>74</b>

42.

5.19.1 If you selected “activity should not continue”, please give your reason:

	Response Percent	Response Count
Work has already been achieved 	2.2%	1
Too expensive 	21.7%	10
<b>Duplicates work done elsewhere</b> 	<b>67.4%</b>	<b>31</b>
Other (please specify) 	8.7%	4
<i>answered question</i>		<b>46</b>
<i>skipped question</i>		<b>384</b>


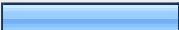
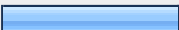
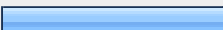
43.

5.20

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing expert training on NMDs to healthcare professionals in countries with poorer access to specialist services.	<b>56.1% (198)</b>	34.6% (122)	5.7% (20)	3.7% (13)	353
<i>answered question</i>					<b>353</b>
<i>skipped question</i>					<b>77</b>

44.

5.20.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		7.1%	2
Too expensive		28.6%	8
Duplicates work done elsewhere		28.6%	8
Other (please specify)		35.7%	10
<i>answered question</i>			<b>28</b>
<i>skipped question</i>			<b>402</b>

45.

5.21

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing good clinical practice (GCP) training.	39.9% (141)	<b>40.5% (143)</b>	13.6% (48)	5.9% (21)	353
<i>answered question</i>					<b>353</b>
<i>skipped question</i>					<b>77</b>

46.

5.21.1 If you selected “activity should not continue”, please give your reason:

	Response Percent	Response Count
Work has already been achieved	5.6%	3
Too expensive	13.0%	7
<b>Duplicates work done elsewhere</b>	<b>68.5%</b>	<b>37</b>
Other (please specify)	13.0%	7
<b>answered question</b>		<b>54</b>
<b>skipped question</b>		<b>376</b>

47.

5.22

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing specialist training on trial design (special focus on NMD trials and the challenges of trials in small populations).	<b>46.6% (166)</b>	39.6% (141)	7.0% (25)	6.7% (24)	356
<b>answered question</b>					<b>356</b>
<b>skipped question</b>					<b>74</b>

48.

5.22.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		10.7%	3
Too expensive		14.3%	4
<b>Duplicates work done elsewhere</b>		<b>50.0%</b>	<b>14</b>
Other (please specify)		25.0%	7
<i>answered question</i>			<b>28</b>
<i>skipped question</i>			<b>402</b>

49.

5.23

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Developing a standardized curriculum for specialist medical training in myology in Europe.	30.7% (109)	<b>48.2% (171)</b>	8.2% (29)	13.0% (46)	355
<i>answered question</i>					<b>355</b>
<i>skipped question</i>					<b>75</b>

50.

5.23.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		11.1%	4
Too expensive		5.6%	2
<b>Duplicates work done elsewhere</b>		<b>50.0%</b>	<b>18</b>
Other (please specify)		33.3%	12
<i>answered question</i>			<b>36</b>
<i>skipped question</i>			<b>394</b>



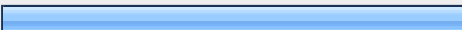

51.

5.24

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Maintaining a website providing independent expert information for patients and families, healthcare professionals, researchers, and industry <a href="http://www.treat-nmd.eu">www.treat-nmd.eu</a>	<b>68.2% (242)</b>	26.5% (94)	3.9% (14)	1.4% (5)	355
<i>answered question</i>					<b>355</b>
<i>skipped question</i>					<b>75</b>

52.

5.24.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		15.0%	3
Too expensive		5.0%	1
Duplicates work done elsewhere		75.0%	15
Other (please specify)		5.0%	1
<i>answered question</i>			<b>20</b>
<i>skipped question</i>			<b>410</b>



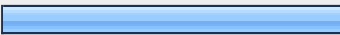
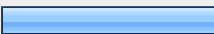
53.

5.25

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing online tools for collaboration between research groups (intranet, filesharing etc.)	<b>50.8% (180)</b>	36.2% (128)	7.1% (25)	5.9% (21)	354
<i>answered question</i>					<b>354</b>
<i>skipped question</i>					<b>76</b>

54.

5.25.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		6.9%	2
Too expensive		3.4%	1
Duplicates work done elsewhere		55.2%	16
Other (please specify)		34.5%	10
<i>answered question</i>			<b>29</b>
<i>skipped question</i>			<b>401</b>

55.

5.26

	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing updates by means of regular newsletters <a href="http://www.treat-nmd.eu/newsletter">www.treat-nmd.eu/newsletter</a>	53.4% (189)	41.2% (146)	3.7% (13)	1.7% (6)	354
<i>answered question</i>					<b>354</b>
<i>skipped question</i>					<b>76</b>

56.

5.26.1 If you selected “activity should not continue”, please give your reason:

		Response Percent	Response Count
Work has already been achieved		15.4%	2
Too expensive		23.1%	3
Duplicates work done elsewhere		23.1%	3
Other (please specify)		38.5%	5
<i>answered question</i>			13
<i>skipped question</i>			417



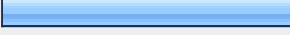
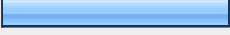
57.

5.27


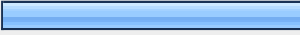
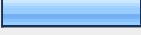


	Top priority	Secondary priority	Activity should not continue	No opinion	Response Count
Providing a forum for discussion and debate on social and ethical issues for both patients and professionals <a href="http://www.treat-nmd.eu/ethics">www.treat-nmd.eu/ethics</a>	31.4% (111)	53.1% (188)	8.2% (29)	7.3% (26)	354
<i>answered question</i>					354
<i>skipped question</i>					76

58.

5.27.1 If you selected “activity should not continue”, please give your reason:

	Response Percent	Response Count
Work has already been achieved 	13.3%	4
Too expensive 	3.3%	1
<b>Duplicates work done elsewhere</b> 	<b>46.7%</b>	<b>14</b>
Other (please specify) 	36.7%	11
<i>answered question</i>		<b>30</b>
<i>skipped question</i>		<b>400</b>

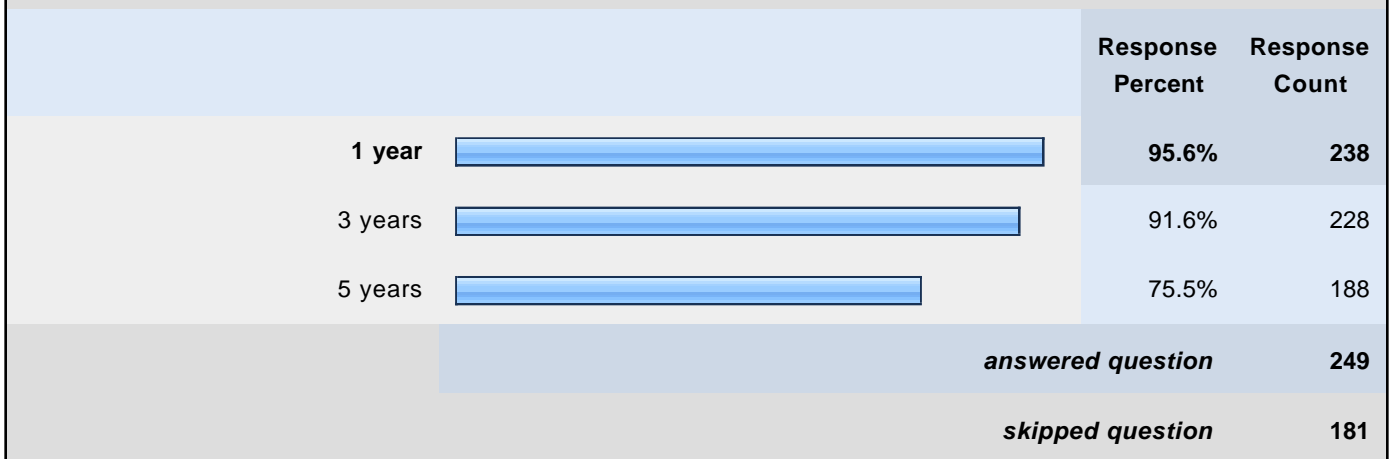
59. 6.1 What other activities not mentioned above should TREAT-NMD focus on in future? Please detail the activity and explain why TREAT-NMD is the appropriate body.

	Response Percent	Response Count
One 	100.0%	107
Two 	48.6%	52
Three 	22.4%	24
Four 	8.4%	9
Five 	2.8%	3
<i>answered question</i>		<b>107</b>
<i>skipped question</i>		<b>323</b>

**60. 7.1 What is your primary area of interest in neuromuscular disease? (Please indicate the disease or specific area of research or care you are most involved in.)**

	Response Count
	298
<i>answered question</i>	<b>298</b>
<i>skipped question</i>	132

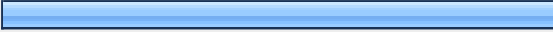

**61. 7.2 Please summarize what needs to be achieved in your area of interest in (a) 1 year, (b) 3 years and (c) 5 years from now.**



**62. 7.3 How would you define the “roadmap” or sequence of concrete steps towards achieving the above goals?**

	Response Count
	159
<i>answered question</i>	<b>159</b>
<i>skipped question</i>	271

**63. 7.4 Are TREAT-NMD tools, services and infrastructure useful in the achievement of the above goals?**

	Response Percent	Response Count
Yes 	90.2%	238
No 	9.8%	26
Please explain your response		154
<i>answered question</i>		264
<i>skipped question</i>		166

**64. TREAT-NMD aims to promote international research collaborations and make it easier for different groups to share information and work together. What additional specific measures should TREAT-NMD put in place to facilitate effective international research collaborations in future?**

	Response Count
	147
<i>answered question</i>	147
<i>skipped question</i>	283

**65. 9. What specific measures should TREAT-NMD put in place to ensure its stakeholders have an adequate voice at a strategic level?**

	Response Count
	138
<i>answered question</i>	138
<i>skipped question</i>	292

**66. 10. What specific measures should TREAT-NMD put in place to ensure it retains its current independence?**

	Response Count
	149
<i>answered question</i>	149
<i>skipped question</i>	281



**67. 11. What specific measures should TREAT-NMD put in place to ensure active ideas generation can come from anywhere within the neuromuscular field?**

	Response Count
	153
<i>answered question</i>	153
<i>skipped question</i>	277

**68. 12. What specific measures should TREAT-NMD put in place to ensure its initiatives are well integrated and harmonized with those of other stakeholders active in the field?**

	Response Count
	124
<i>answered question</i>	124
<i>skipped question</i>	306

**69. 13. One possible model for the future structure envisages the creation of a board of directors to provide oversight and an executive committee made up of representatives of the institutions carrying out the work. In such a model, should strategic decisions be taken by:**

	Response Percent	Response Count
13.1 The board of directors 	10.7%	26
13.2 The executive committee 	11.9%	29
<b>13.3 Both bodies, with respective responsibilities defined contractually</b> 	<b>77.5%</b>	<b>189</b>
Please provide any further comments on responsibility for strategic decisions here.		40
<i>answered question</i>		<b>244</b>
<i>skipped question</i>		<b>186</b>

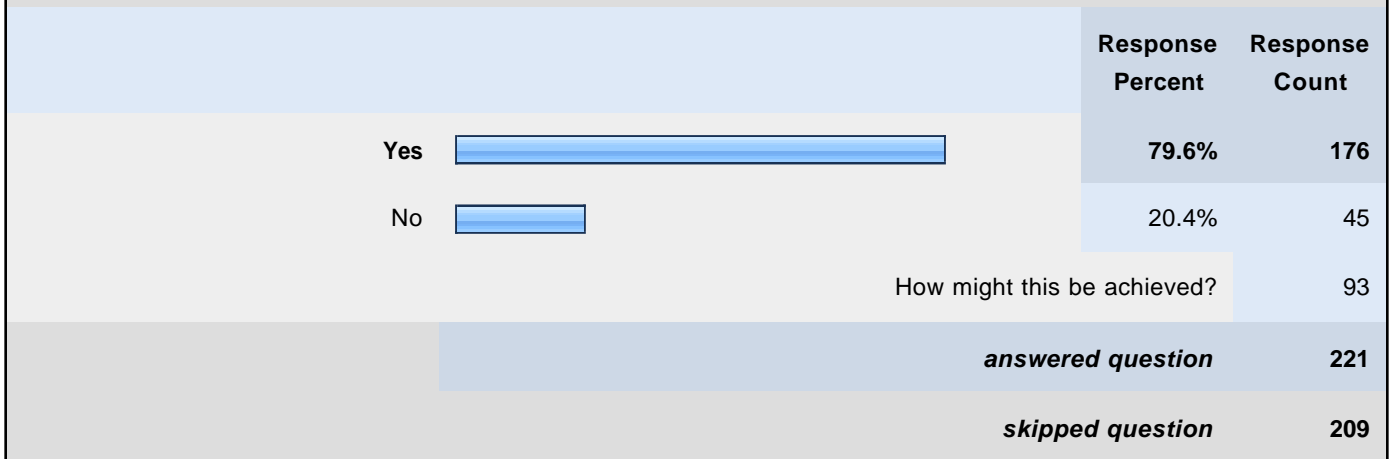
**70. 14. If you have any other comments about the future governance and oversight structure, please provide them here.**

	Response Count
	39
<i>answered question</i>	
<i>skipped question</i>	
	<b>39</b>
	<b>391</b>

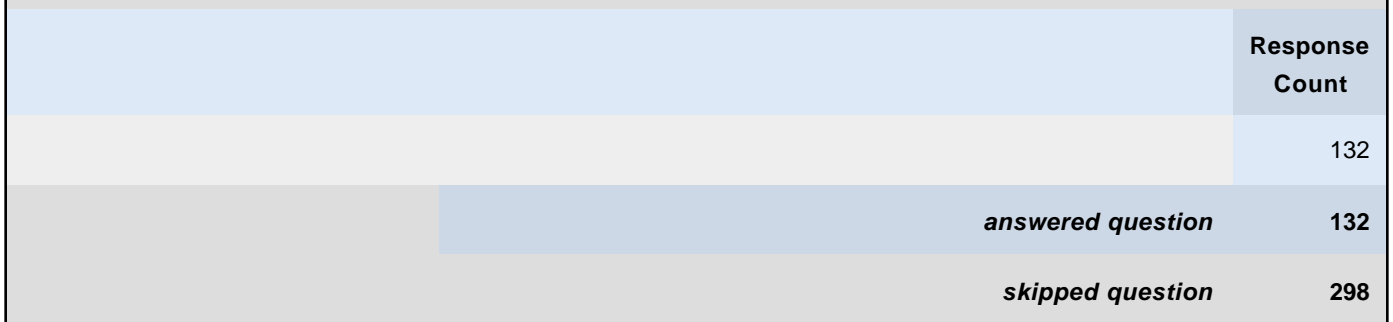
**71. 16.1 What rights/benefits should such funders expect as a return on their investment?**

	Response Count
	177
<i>answered question</i>	
<i>skipped question</i>	
	<b>177</b>
	<b>253</b>

**72. 16.2 Is there a need to enable organizations to provide project-specific funding targeted at individual TREAT-NMD activities?**



**73. 16.3 How might funding to sustain the overall infrastructure and services, including management, coordination and administrative activities, be obtained?**



**74. 17.1 Should TREAT-NMD ask industry to pay for services?**



**75. 17.2 Should industry sponsor meetings associated with TREAT-NMD?**

	Response Count
	217
<i>answered question</i>	217
<i>skipped question</i>	213

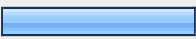
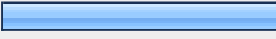
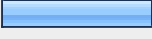
**76. 17.3 Would it be appropriate for industry to contribute to the future funding of TREAT-NMD in other ways? If so, which? If not, why not?**

	Response Count
	163
<i>answered question</i>	163
<i>skipped question</i>	267

**77. 17.4 How else could TREAT-NMD develop its services for industry?**

	Response Count
	93
<i>answered question</i>	93
<i>skipped question</i>	337

**78. 18.1 Should TREAT-NMD consider initiating membership fees to cover some of its operational costs (as many professional societies and charitable bodies do)?**

	Response Percent	Response Count
Immediately after the end of the EU funding 	31.1%	80
Not immediately but maybe in a few more years 	44.7%	115
Never 	24.1%	62
Please explain your response		147
<b>answered question</b>		<b>257</b>
<b>skipped question</b>		<b>173</b>

**79. 19.1 Please provide any other comments about the future funding of TREAT-NMD here.**

	Response Count
	46
<b>answered question</b>	<b>46</b>
<b>skipped question</b>	<b>384</b>







**80. 20. Is there anything else you'd like to tell us about your views on the future of TREAT-NMD?**

	Response Count
	47
<b>answered question</b>	<b>47</b>
<b>skipped question</b>	<b>383</b>









81. 21.1 Name	
	Response Count
	235
<i>answered question</i>	235
<i>skipped question</i>	195

82. 21.2 Email Address	
	Response Count
	236
<i>answered question</i>	236
<i>skipped question</i>	194

### 83. 21.3 Country in which you are living at present.

	Response Percent	Response Count
ac – Ascension Island	0.0%	0
ad – Andorra	0.0%	0
ae – United Arab Emirates	0.0%	0
af – Afghanistan	0.0%	0
ag – Antigua and Barbuda	0.0%	0
ai – Anguilla	0.0%	0
al – Albania	0.0%	0
am – Armenia	0.0%	0
an – Netherlands Antilles	0.0%	0
ao – Angola	0.0%	0
aq – Antarctica	0.0%	0
ar – Argentina 	0.7%	2
as – American Samoa	0.0%	0
at – Austria 	1.9%	5
au – Australia 	5.2%	14
aw – Aruba	0.0%	0
ax – Aland Islands 	0.4%	1
az – Azerbaijan	0.0%	0
ba – Bosnia and Herzegovina	0.0%	0
bb – Barbados	0.0%	0
bd – Bangladesh	0.0%	0
be – Belgium 	1.9%	5
bf – Burkina Faso	0.0%	0
bg – Bulgaria 	0.4%	1
bh – Bahrain	0.0%	0
bi – Burundi	0.0%	0
bj – Benin	0.0%	0








bm – Bermuda	0.0%	0
bn – Brunei Darussalam	0.0%	0
bo – Bolivia	0.0%	0
br – Brazil 	2.6%	7
bs – Bahamas	0.0%	0
bt – Bhutan	0.0%	0
bv – Bouvet Island	0.0%	0
bw – Botswana	0.0%	0
by – Belarus	0.0%	0
bz – Belize	0.0%	0
ca – Canada 	1.5%	4
cc – Cocos (Keeling) Islands	0.0%	0
cd – Congo, The Democratic Republic of the	0.0%	0
cf – Central African Republic	0.0%	0
cg – Congo, Republic of	0.0%	0
ch – Switzerland 	1.9%	5
ci – Cote d'Ivoire	0.0%	0
ck – Cook Islands	0.0%	0
cl – Chile	0.0%	0
cm – Cameroon	0.0%	0
cn – China 	0.4%	1
co – Colombia	0.0%	0
cr – Costa Rica	0.0%	0
cu – Cuba	0.0%	0
cv – Cape Verde	0.0%	0
cx – Christmas Island	0.0%	0
cy – Cyprus	0.0%	0
cz – Czech Republic 	1.9%	5





de – Germany		10.7%	29
dj – Djibouti		0.0%	0
dk – Denmark		0.7%	2
dm – Dominica		0.0%	0
do – Dominican Republic		0.0%	0
dz – Algeria		0.0%	0
ec – Ecuador		0.0%	0
ee – Estonia		0.0%	0
eg – Egypt		0.0%	0
eh – Western Sahara		0.0%	0
er – Eritrea		0.0%	0
es – Spain		3.3%	9
et – Ethiopia		0.0%	0
eu – European Union		0.7%	2
fi – Finland		1.1%	3
fj – Fiji		0.0%	0
fk – Falkland Islands (Malvinas)		0.0%	0
fm – Micronesia, Federated States of		0.0%	0
fo – Faroe Islands		0.0%	0
fr – France		4.1%	11
ga – Gabon		0.0%	0
gb – United Kingdom		0.4%	1
gd – Grenada		0.0%	0
ge – Georgia		0.4%	1
gf – French Guiana		0.0%	0
gg – Guernsey		0.0%	0
gh – Ghana		0.0%	0
gi – Gibraltar		0.0%	0
gl – Greenland		0.0%	0

gm – Gambia	0.0%	0
gn – Guinea	0.0%	0
gp – Guadeloupe	0.0%	0
gq – Equatorial Guinea	0.0%	0
gr – Greece	0.4%	1
gs – South Georgia and the South Sandwich Islands	0.0%	0
gt – Guatemala	0.0%	0
gu – Guam	0.0%	0
gw – Guinea-Bissau	0.0%	0
gy – Guyana	0.0%	0
hk – Hong Kong	0.0%	0
hm – Heard and McDonald Islands	0.0%	0
hn – Honduras	0.0%	0
hr – Croatia/Hrvatska	0.7%	2
ht – Haiti	0.0%	0
hu – Hungary	0.7%	2
id – Indonesia	0.0%	0
ie – Ireland	0.7%	2
il – Israel	1.5%	4
im – Isle of Man	0.0%	0
in – India	1.9%	5
io – British Indian Ocean Territory	0.0%	0
iq – Iraq	0.0%	0
ir – Iran, Islamic Republic of	0.4%	1
is – Iceland	0.0%	0
it – Italy	8.9%	24
je – Jersey	0.0%	0
jm – Jamaica	0.4%	1
jo – Jordan	0.0%	0

jp – Japan	0.4%	1
ke – Kenya	0.0%	0
kg – Kyrgyzstan	0.0%	0
kh – Cambodia	0.0%	0
ki – Kiribati	0.0%	0
km – Comoros	0.0%	0
kn – Saint Kitts and Nevis	0.0%	0
kp – Korea, Democratic People's Republic	0.0%	0
kr – Korea, Republic of	0.0%	0
kw – Kuwait	0.0%	0
ky – Cayman Islands	0.0%	0
kz – Kazakhstan	0.0%	0
la – Lao People's Democratic Republic	0.0%	0
lb – Lebanon	0.0%	0
lc – Saint Lucia	0.0%	0
li – Liechtenstein	0.0%	0
lk – Sri Lanka	0.0%	0
lr – Liberia	0.0%	0
ls – Lesotho	0.0%	0
lt – Lithuania	0.7%	2
lu – Luxembourg	0.0%	0
lv – Latvia	0.4%	1
ly – Libyan Arab Jamahiriya	0.0%	0
ma – Morocco	0.0%	0
mc – Monaco	0.0%	0
md – Moldova, Republic of	0.0%	0
me – Montenegro	0.0%	0
mg – Madagascar	0.0%	0
mh – Marshall Islands	0.0%	0

mk – Macedonia, The Former Yugoslav Republic of	0.4%	1
ml – Mali	0.0%	0
mm – Myanmar	0.0%	0
mn – Mongolia	0.0%	0
mo – Macao	0.0%	0
mp – Northern Mariana Islands	0.0%	0
mq – Martinique	0.0%	0
mr – Mauritania	0.0%	0
ms – Montserrat	0.0%	0
mt – Malta	0.0%	0
mu – Mauritius	0.0%	0
mv – Maldives	0.0%	0
mw – Malawi	0.0%	0
mx – Mexico	0.4%	1
my – Malaysia	0.0%	0
mz – Mozambique	0.0%	0
na – Namibia	0.0%	0
nc – New Caledonia	0.0%	0
ne – Niger	0.0%	0
nf – Norfolk Island	0.0%	0
ng – Nigeria	0.0%	0
ni – Nicaragua	0.0%	0
nl – Netherlands	4.8%	13
no – Norway	0.7%	2
np – Nepal	0.0%	0
nr – Nauru	0.0%	0
nu – Niue	0.0%	0
nz – New Zealand	0.7%	2
om – Oman	0.0%	0

pa – Panama	0.0%	0
pe – Peru	0.0%	0
pf – French Polynesia	0.0%	0
pg – Papua New Guinea	0.0%	0
ph – Philippines	0.0%	0
pk – Pakistan	0.0%	0
pl – Poland 	1.1%	3
pm – Saint Pierre and Miquelon	0.0%	0
pn – Pitcairn Island	0.0%	0
pr – Puerto Rico	0.0%	0
ps – Palestinian Territory, Occupied	0.0%	0
pt – Portugal 	1.1%	3
pw – Palau	0.0%	0
py – Paraguay	0.0%	0
qa – Qatar	0.0%	0
re – Reunion Island	0.0%	0
ro – Romania 	1.1%	3
rs – Serbia 	0.4%	1
ru – Russian Federation 	1.9%	5
rw – Rwanda	0.0%	0
sa – Saudi Arabia	0.0%	0
sb – Solomon Islands	0.0%	0
sc – Seychelles	0.0%	0
sd – Sudan	0.0%	0
se – Sweden 	1.9%	5
sg – Singapore	0.0%	0
sh – Saint Helena	0.0%	0
si – Slovenia 	0.4%	1
sj – Svalbard and Jan Mayen Islands	0.0%	0

sk – Slovak Republic	0.0%	0
sl – Sierra Leone	0.0%	0
sm – San Marino	0.0%	0
sn – Senegal	0.0%	0
so – Somalia	0.0%	0
sr – Suriname	0.0%	0
st – Sao Tome and Principe	0.0%	0
su – Soviet Union	0.0%	0
sv – El Salvador	0.0%	0
sy – Syrian Arab Republic	0.0%	0
sz – Swaziland	0.0%	0
tc – Turks and Caicos Islands	0.0%	0
td – Chad	0.0%	0
tf – French Southern Territories	0.0%	0
tg – Togo	0.0%	0
th – Thailand 	0.4%	1
tj – Tajikistan	0.0%	0
tk – Tokelau	0.0%	0
tl – Timor-Leste	0.0%	0
tm – Turkmenistan	0.0%	0
tn – Tunisia	0.0%	0
to – Tonga	0.0%	0
tp – East Timor	0.0%	0
tr – Turkey 	3.0%	8
tt – Trinidad and Tobago	0.0%	0
tv – Tuvalu	0.0%	0
tw – Taiwan 	0.4%	1
tz – Tanzania	0.0%	0
ua – Ukraine 	0.4%	1

ug – Uganda	0.0%	0
uk – United Kingdom	8.9%	24
um – United States Minor Outlying Islands	0.0%	0
<b>us – United States</b>	<b>14.8%</b>	<b>40</b>
uy – Uruguay	0.0%	0
uz – Uzbekistan	0.0%	0
va – Holy See (Vatican City State)	0.0%	0
vc – Saint Vincent and the Grenadines	0.0%	0
ve – Venezuela	0.0%	0
vg – Virgin Islands, British	0.0%	0
vi – Virgin Islands, U.S.	0.0%	0
vn – Vietnam	0.0%	0
vu – Vanuatu	0.0%	0
wf – Wallis and Futuna Islands	0.0%	0
ws – Samoa	0.0%	0
ye – Yemen	0.0%	0
yt – Mayotte	0.0%	0
yu – Yugoslavia	0.4%	1
za – South Africa	0.0%	0
zm – Zambia	0.0%	0
zw – Zimbabwe	0.0%	0
	<b>answered question</b>	<b>270</b>
	<b>skipped question</b>	<b>160</b>

**84. 22.1 Which of the following best describes your current role?  
(Please tick all that apply)**

		Response Percent	Response Count
22.1.1 Scientist	<input type="checkbox"/>	39.6%	113
<b>22.1.2 Clinician</b>	<input checked="" type="checkbox"/>	<b>44.2%</b>	<b>126</b>
22.1.3 Other healthcare professional	<input type="checkbox"/>	9.5%	27
22.1.4 Affected person/patient	<input type="checkbox"/>	4.9%	14
22.1.5 Parent or other relative	<input type="checkbox"/>	15.8%	45
22.1.6 Patient organization representative	<input type="checkbox"/>	16.1%	46
22.1.7 Industry representative	<input type="checkbox"/>	2.1%	6
22.1.8 Government/health authority/regulatory representative	<input type="checkbox"/>	1.8%	5
	22.1.9 Other (please specify)		25
<b>answered question</b>			<b>285</b>
<b>skipped question</b>			<b>145</b>

**85. 22.2 Which of the following best describes the type of organization you represent? (Please tick one box only)**

	Response Percent	Response Count
<b>22.2.1 Academic</b> <input checked="" type="checkbox"/>	<b>40.7%</b>	<b>118</b>
22.2.2 Clinical <input checked="" type="checkbox"/>	24.8%	72
22.2.3 Biotech company <input type="checkbox"/>	2.8%	8
22.2.4 Large pharma <input type="checkbox"/>	0.7%	2
22.2.5 Learned society <input type="checkbox"/>	0.3%	1
22.2.6 Public sector funder <input type="checkbox"/>	1.7%	5
22.2.7 Charitable funder <input type="checkbox"/>	3.8%	11
22.2.8 Patient group <input checked="" type="checkbox"/>	19.3%	56
22.2.9 Government <input type="checkbox"/>	0.7%	2
22.2.10 Other (please specify) <input type="checkbox"/>	5.2%	15
<b>answered question</b>		<b>290</b>
<b>skipped question</b>		<b>140</b>

**86. 22.3 Which of the following best describes your current role? (Please tick all that apply)**

	Response Percent	Response Count
22.3.1 Basic research <input checked="" type="checkbox"/>	33.0%	93
22.3.2 Clinical trials <input checked="" type="checkbox"/>	35.5%	100
<b>22.3.3 Patient care</b> <input checked="" type="checkbox"/>	<b>54.6%</b>	<b>154</b>
22.3.4 Ethics and social issues <input type="checkbox"/>	9.6%	27
22.3.5 Translational medicine <input checked="" type="checkbox"/>	24.5%	69
22.3.6 Regulatory issues <input type="checkbox"/>	6.4%	18
22.3.7 Other (please specify) <input type="checkbox"/>	14.9%	42
<b>answered question</b>		<b>282</b>
<b>skipped question</b>		<b>148</b>