

## YouGov Survey Results

Sample Size: 100 UK MPs  
Fieldwork: 27/06/13 - 10/07/13

Total	Party			
	Conservative	Labour	Liberal Democrat	Other

**BIA1\_1. Access to treatments on the NHS for very rare diseases should be based on clinical need and not the NHS's ability to pay : To what extent do you agree or disagree with each of these statements?**

Unweighted base	100	50	41	6	3
<b>Base</b>	100	47	39	9	5
Strongly agree	23%	10%	34%	24%	71%
Agree	45%	48%	45%	45%	29%
Neither agree nor disagree	16%	25%	11%	-	-
Disagree	10%	9%	8%	31%	-
Strongly disagree	3%	4%	2%	-	-
Don't know	3%	6%	-	-	-
Total % Agree	69%	57%	79%	69%	100%
Total % Disagree	13%	12%	10%	31%	-

**BIA1\_2. 'NICE (the National Institute for Health and Care Excellence) should apply its standard mathematical methodology to very rare diseases, even if this results in more new effective treatments being rejected' : To what extent do you agree or disagree with each of these statements?**

Unweighted base	100	50	41	6	3
<b>Base</b>	100	47	39	9	5
Strongly agree	3%	2%	4%	-	-
Agree	18%	16%	23%	-	29%
Neither agree nor disagree	26%	28%	26%	31%	-
Disagree	37%	36%	26%	69%	71%
Strongly disagree	8%	7%	12%	-	-
Don't know	9%	12%	9%	-	-
Total % Agree	20%	18%	27%	-	29%
Total % Disagree	45%	42%	38%	69%	71%

**BIA1\_3. Funding for treating patients with very rare diseases should be ring-fenced within the NHS budget : To what extent do you agree or disagree with each of these statements?**

Unweighted base	100	50	41	6	3
<b>Base</b>	100	47	39	9	5
Strongly agree	6%	3%	13%	-	-
Agree	24%	31%	15%	-	71%
Neither agree nor disagree	28%	24%	27%	54%	29%
Disagree	32%	32%	33%	46%	-
Strongly disagree	5%	4%	8%	-	-
Don't know	4%	7%	3%	-	-
Total % Agree	30%	34%	28%	-	71%
Total % Disagree	37%	36%	41%	46%	-

**BIA1\_4. There should be a maximum price per patient for treating people with very rare and complex diseases : To what extent do you agree or disagree with each of these statements?**

Unweighted base	100	50	41	6	3
<b>Base</b>	100	47	39	9	5
Strongly agree	1%	-	3%	-	-
Agree	8%	7%	11%	-	-
Neither agree nor disagree	18%	27%	10%	16%	-
Disagree	39%	34%	34%	69%	71%
Strongly disagree	24%	18%	33%	15%	29%
Don't know	10%	14%	9%	-	-
Total % Agree	9%	7%	14%	-	-
Total % Disagree	63%	52%	67%	84%	100%

All figures, unless otherwise stated, are from YouGov Plc.

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No.	PARTY	BIA2. If you wish to add any further comments about this issue then please add them here.
23	Conservative	- This is a very difficult issue. Only British residents should be supported financially from the state.
7	Conservative	DK
11	Conservative	DK
13	Conservative	DK
17	Conservative	DK
25	Conservative	DK
30	Conservative	DK
38	Conservative	DK
40	Conservative	DK
54	Conservative	DK
57	Conservative	DK
64	Conservative	DK
66	Conservative	DK
71	Conservative	DK
77	Conservative	DK
85	Conservative	DK
96	Conservative	DK
32	Labour	DK
35	Labour	DK
43	Labour	DK
49	Labour	DK
53	Labour	DK
76	Labour	DK
82	Labour	DK
91	Labour	DK
98	Labour	DK
62	Conservative	complicated issue that cannot be answered competently with the tick boxes offered
3	Labour	I think its effectiveness not price that should be the criterion
72	Liberal Democrat	I'm not sure if 'standard' NICE methodology is appropriate for something which is by definition unusual but I don't think we can afford to ring-fence rarer conditions or write a blank cheque that we will fund their treatment without limit according to need. They may have a right to special treatment because of rarity but they do not have a greater moral call on resources than people suffering from heart disease or cancer.
24	Other	Medical treatment, whatever the condition, must be on medical need not ability to pay or cost
5	Conservative	More assistance needs to be given to research which is highlighting ways of treating rare diseases. In the long term this is very cost effective.
6	Labour	No
9	Labour	no
19	Conservative	No further comment.
4	Labour	We need to modernise our health and care services efficiently to ensure that we can afford the drugs of the future.
45	Conservative	We should look at what other countries do to manage finite health resources.
37	Labour	With rare diseases, medicines haven't always been trialled - due to the lack of opportunity to test them as so few people have them. As an MP I have had many cases where the PCT have refused funding for potentially life saving drugs because of minimal testing - but if funding is not given, they will never be widely tested - it is a vicious circle.
1	Conservative	
2	Conservative	
10	Conservative	
14	Conservative	
15	Conservative	
16	Conservative	
18	Conservative	
21	Conservative	
28	Conservative	
33	Conservative	
36	Conservative	
39	Conservative	
46	Conservative	
48	Conservative	
55	Conservative	
59	Conservative	
63	Conservative	
67	Conservative	
69	Conservative	
73	Conservative	
74	Conservative	
78	Conservative	
79	Conservative	
83	Conservative	
86	Conservative	
87	Conservative	
88	Conservative	
94	Conservative	
95	Conservative	
8	Labour	
12	Labour	
20	Labour	
22	Labour	
26	Labour	
29	Labour	
31	Labour	
34	Labour	
42	Labour	
47	Labour	
50	Labour	
51	Labour	
52	Labour	
56	Labour	
58	Labour	
60	Labour	
61	Labour	
68	Labour	
75	Labour	
81	Labour	
84	Labour	
90	Labour	
92	Labour	
93	Labour	
97	Labour	
99	Labour	
100	Labour	
41	Liberal Democrat	
44	Liberal Democrat	
65	Liberal Democrat	
70	Liberal Democrat	
80	Liberal Democrat	
27	Other	
89	Other	