Absolutes/col percents

Page 1

Table 1 Q1. Which one of these regions do you live in? Base: All respondents

		Ger	nder			Ag	le				Social (Grade		Employ Sect		Reg	ion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Wales	1002 50%	516 50%	486 50%	123 51%	149 48%	157 49%	175 49%	157 50%	240 53%	344 48%	310 53%	134 48%	214 50%	184 52%	361 49%	1002 100%p	-
Scotland	1001 50%	522 50%	479 50%	118 49%	159 52%	166 51%	186 51%	155 50%	217 47%	368 52%	279 47%	143 52%	210 50%	168 48%	379 51%	-	1001 100%o

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

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Absolutes/col percents

Table 2 Q2. Age Base: All respondents

		Gen	der			Age					Social G	arade		Employ Sec	tor	Reg	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
18-24	241 12%	64 6%	177 18%a	241 100%defgl	- h -	-	-	-	-	53 7%	121 21%ikl	24 9%	42 10%	23 6%	87 12%m	123 12%	118 12%
25-34	308 15%	129 12%	180 19%a	-	308 100%cefg	- h -	-	-	-	114 16%	86 15%	48 17%	61 14%	72 20%	171 23%	149 15%	159 16%
35-44	322 16%	172 17%	150 16%	-	-	322 100%cdfg	- h -	-	-	105 15%	96 16%	49 18%	72 17%	101 29%n	151 20%	157 16%	166 17%
45-54	362 18%	188 18%	174 18%	-	-	-	362 100%cc	- degh -	-	103 14%	98 17%	67 24%ij	94 22%ij	97 28%	180 24%	175 18%	186 19%
55-64	312 16%	208 20%b	105 11%	-	-	-	-	312 100%cdef	- h -	114 16%	74 13%	48 17%	77 18%j	48 14%	103 14%	157 16%	155 15%
65+	457 23%	278 27%b	179 19%	-	-	-	-	-	457 100%cde g	224 f 31%jkl	113 19%	41 15%	78 18%	11 3%	49 7%m	240 24%	217 22%
Mean	47.80	51.38b	43.94	21.24	30.37c	39.83cd	49.57cd		69.72cd fg I	51.01jk	44.34	47.01j	47.71j	42.85	42.39	48.06	47.53
Standard deviation Standard error	16.84 0.38	15.73 0.50	17.16 0.54	1.76 0.12	2.78 0.16	2.82 0.15	3.00 0.16	2.79 0.15	4.18 0.20	17.10 0.64	17.45 0.72	15.09 0.90	15.63 0.75	11.62 0.62	13.64 0.50	17.01 0.54	16.68 0.53

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

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Absolutes/col percents

Page 3

Table 3 Q3. Gender Base: All respondents

		Gen	der			Age					Social G	irade		Employ Sect		Reg	ion
	Total	Male (a)	Female (b)	18-24 2 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Male	1038 52%	1038 100%b	-	64 27%	129 42%c	172 53%cd	188 52%cd	208 67%cdet	278 f 61%cde	416 f 58%jl	292 50%	144 52%l	186 44%	164 47%	423 57%m	516 51%	522 52%
Female	965 48%	-	965 100%a	177 73%defg h	180 58%efgh	150 1 47%gh	174 48%gh	105 33%	179 39%	297 42%	297 50%i	133 48%	238 56%ik	188 53%n	318 43%	486 49%	479 48%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p



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Absolutes/col percents

Table 4 Q4. Social Grade Base: All respondents

		Gen	der			Age					Social G	rade		Employr Secto	or	Reg	
	Total	Male (a)	Female (b)	18-24 2 (c)	25-34 ((d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
A	209 10%	127 12%b	82 8%	20 8%	16 5%	30 9%d	24 7%	39 12%df	81 18%cde g	209 f 29%jkl	-	-	-	31 9%	65 9%	94 9%	114 11%
В	504 25%	289 28%b	215 22%	33 14%	98 32%cefg	75 23%c	79 22%c	75 24%c	144 31%cefç	504 g 71%jkl	-	-	-	120 34%n	181 24%	250 25%	254 25%
C1	589 29%	292 28%	297 31%	121 50%defg h	86 28%	96 30%	98 27%	74 24%	113 25%	-	589 100%ikl	-	-	117 33%	238 32%	310 31%	279 28%
C2	277 14%	144 14%	133 14%	24 10%	48 15%h	49 15%h	67 19%ch	48 15%h	41 9%	-	-	277 100%ijl	-	45 13%	146 20%m	134 13%	143 14%
D	197 10%	84 8%	113 12%a	25 11%h	40 13%h	32 10%h	44 12%h	30 10%h	26 6%	-	-	-	197 46%ijk	37 11%	108 15%	107 11%	90 9%
E	228 11%	103 10%	125 13%a	17 7%	21 7%	40 12%cd	50 14%cd	47 15%cd	52 11%d	-	-	-	228 54%ijk	2 1%	3 *	107 11%	120 12%
NET: AB	712 36%	416 40%b	297 31%	53 22%	114 37%cf	105 32%c	103 28%	114 36%cf	224 49%cde fg	712 100%jkl	-	-	-	151 43%n	246 33%	344 34%	368 37%
NET: DE	424 21%	186 18%	238 25%a	42 18%	61 20%	72 22%	94 26%ch	77 25%h	78 17%	-	-	-	424 100%ijk	39 11%	111 15%	214 21%	210 21%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

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Absolutes/col percents

Table 5

Q5a. Which of the following best describes your current working status? Base: All respondents

		Gen	ıder			Age					Social G	irade		Employ Sect	or	Reg	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 	35-44 (e)	45-54 (f)	55-64 	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: Working	1092 55%	587 57%	505 52%	110 45%h	243 79%cgh	253 78%cgh	277 1 77%cgh	151 48%h	59 13%	397 56%l	355 60%l	190 69%ijl	150 35%	352 100%	740 100%	545 54%	547 55%
Working full time - working 30 hours per week or more	785 39%	483 47%b	302 31%	62 26%h	199 65%cgh	194 60%cgh	209 58%cgh	105 34%h	15 3%	311 44%l	261 44%l	128 46%l	85 20%	270 77%n	514 69%	389 39%	395 39%
Working part time - working between 8 and 29 hours per week	308 15%	104 10%	204 21%a	48 20%h	44 14%h	59 18%h	68 19%h	46 15%h	44 10%	86 12%	95 16%i	62 22%ijl	65 15%	82 23%	226 31%m	156 16%	152 15%
NET: Not working	266 13%	120 12%	146 15%a	120 50%def h	34 g 11%h	41 13%h	36 10%h	35 11%h	1 *	42 6%	93 16%ik	13 5%	118 28%ijk	-	-	123 12%	143 14%
Not working but seeking work or temporarily unemployed or sick	106 5%	53 5%	54 6%	20 8%gh	23 8%h	27 8%gh	23 6%h	13 4%h	-	14 2%	19 3%	4 1%	70 17%ijk	-	-	43 4%	63 6%0
Not working and not seeking work / Student	160 8%	67 6%	93 10%a	100 41%defe	11 gh 4%h	14 4%h	13 4%h	22 7%dfh	1 *	29 4%	75 13%ik	9 3%	47 11%ik	-	-	80 8%	80 8%
Retired on a state pension only	88 4%	30 3%	58 6%a	-	-	-	-	9 3%cdef	79 17%cdef	11 g 2%	9 1%	8 3%	59 14%ijk	-	-	48 5%	39 4%
Retired with a private pension	417 21%	280 27%b	137 14%	-	-	1 *	4 1%	98 31%cdef	314 69%cdef g	236 33%jkl	115 19%l	40 14%l	25 6%	-	-	212 21%	205 20%
House person, housewife, househusband, etc.	140 7%	21 2%	119 12%a	12 5%h	32 10%ch	28 9%h	45 13%cgh	20 6%h	4 1%	25 4%	17 3%	25 9%ij	72 17%ijk	-	-	74 7%	66 7%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

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Absolutes/col percents

Page 6

Table 6 Q5b. Do you work in any of the following occupations? Base: All respondents

		Ger	nder			Age	•				Social G	irade		Employ Sect	or	Regi	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (o)	Scot- land (p)
Unweighted base	1088	562	526	95	243	259	270	162	59	396	352	190	150	357	731	550	538
Weighted base	1092	587	505	110*	243	253	277	151	59*	397	355	190	150	352	740	545	547
NET: Public Sector	352 32%	164 28%	188 37%a	23 21%	72 29%	101 40%cdł	97 1 35%ch	48 32%h	11 18%	151 38%kl	117 33%k	45 23%	39 26%	352 100%n	-	184 34%	168 31%
Other public sector occupation (please specify as much detail as possible)	80 7%	36 6%	44 9%	6 6%	10 4%	21 9%d	29 10%d	12 8%	2 3%	24 6%	22 6%	18 9%	16 11%	80 23%n	-	33 6%	47 9%
National Health Service	70 6%	22 4%	48 10%a	9 8%	21 9%	18 7%	16 6%	6 4%	1 2%	26 7%	24 7%	10 5%	10 7%	70 20%n	-	34 6%	36 7%
Teaching employed by local education authority including voluntary aided schools and foundation schools	50 5%	15 3%	35 7%a	5 4%	10 4%	13 5%	10 3%	8 5%	5 8%	36 9%jkl	10 3%	3 2%	1 1%	50 14%n	-	29 5%	21 4%
Local government administration	47 4%	25 4%	23 5%	-	4 2%	17 7%cd	15 6%cd	9 6%cd	2 3%	13 3%	26 7%ikl	4 2%	4 2%	47 13%n	-	28 5%	20 4%
Universities and Academies funded by government	35 3%	18 3%	17 3%	1 1%	11 5%	7 3%	10 4%	5 4%	-	18 5%kl	15 4%kl	1 *	1 1%	35 10%n	-	21 4%	13 2%
Central government including all administrative departments and central government agencies such as the Bank of England	29 3%	19 3%	11 2%	-	5 2%	11 4%c	11 4%c	2 1%	-	19 5%jl	6 2%	3 2%	1 1%	29 8%n	-	17 3%	12 2%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p * small base

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Absolutes/col percents

Table 6 Q5b. Do you work in any of the following occupations? Base: All respondents

		Gen	der			Ag	e				Social G	irade		Employ Sect	or	Reg	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (o)	Scot- land (p)
Weighted base	1092	587	505	110*	243	253	277	151	59*	397	355	190	150	352	740	545	547
Public corporations such as the Royal Mail or British Nuclear fuels or Driving Standards agency	12 1%	10 2%b	2 *		2 1%	4 2%	3 1%	3 2%	-	1 *	2 1%	5 3%ij	4 3%ij	12 3%n	-	7 1%	5 1%
Police service	12 1%	8 1%	4 1%	-	6 2%f	6 2%fg	-	-	-	4 1%	8 2%k	-	-	12 3%n	-	6 1%	6 1%
Public sector housing	8 1%	3 1%	5 1%	1 1%	-	3 1%	3 1%	1 1%	-	4 1%	3 1%	-	1 1%	8 2%n	-	5 1%	3 1%
HM Forces	4 *	4 1%	-	-	2 1%	2 1%	-	-	-	1 *	1 *	1 1%	1 1%	4 1%n	-	1 *	3 1%
Courts service	3 *	3 1%	-	-	-	-	-	2 1%	1 2%def	3 1%	-	-	-	3 1%n	-	2 *	1 *
Bradford and Bingley or Northern Rock Building societies	1 *	1 *	-	-	1 *	-		-	-	1 *		-	-	1 *		1 *	-
None of the above - Private Sector	740 68%	423 72%b	318 63%	87 79%ef	171 71%e	151 60%	180 65%	103 68%	49 82%efg	246 62%	238 67%	146 77%ij	111 74%i	-	740 100%m	361 66%	379 69%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p * small base



Absolutes/col percents

Table 7

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

Summary table

		Patients should have access to a treatment based on clinical need, even if this would be individually costly to the NHS because of the rarity of a disease	The NHS should ensure that patients with very rare diseases have the same access to treatment as patients with common diseases, even if it means savings
Unweighted base		2003	2003
Weighted base		2003	2003
Agree entirely	(10)	700 35%	680 34%
9	(9)	288 14%	253 13%
8	(8)	426 21%	384 19%
7	(7)	245 12%	257 13%
6	(6)	123 6%	159 8%
5	(5)	132 7%	154 8%
4	(4)	24 1%	47 2%
3	(3)	33 2%	30 1%
2	(2)	16 1%	19 1%
1	(1)	3 *	6 *
Do not agree at all	(0)	14 1%	13 1%



Absolutes/col percents

Page 9

Table 7

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

Summary table

	Patients should have access to a treatment based on clinical need, even if this would be individually costly to the NHS because of the rarity of a disease	The NHS should ensure that patients with very rare diseases have the same access to treatment as patients with common diseases, even if it means savings
Weighted base	2003	2003
NET: 8-10	1414 71%	1317 66%
NET: 4-7	523 26%	618 31%
NET: 0-3	66 3%	68 3%
Mean	8.16	7.99
Standard deviation Standard error	1.97 0.04	2.07 0.05



Absolutes/col percents

Table 8

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

Patients should have access to a treatment based on clinical need, even if this would be individually costly to the NHS because of the rarity of a disease

		Ge	ender			Aç	je				Social C	arade		Employ Sect	ment or	Reg	gion
	Tot	al Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (o)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely	(10) 700 35	356 %34%	344 36%	66 27%	101 33%	106 33%	136 38%c	119 38%c	171 37%c	220 31%	186 32%	121 43%ij	173 41%ij	113 32%	250 34%	360 36%	340 34%
9	(9) 288 14	155 %15%	133 14%	28 12%	41 13%	52 16%	53 15%	43 14%	70 15%	124 17%jl	78 13%	35 12%	52 12%	60 17%	99 13%	145 14%	143 14%
8	(8) 426 21	216 %21%	210 22%	56 23%	59 19%	67 21%	85 23%	64 20%	96 21%	146 20%	144 24%k	45 16%	91 22%	74 21%	161 22%	217 22%	209 21%
7	(7) 245 12	124 % 12%	121 12%	41 17%fg	39 13%	45 14%	34 10%	31 10%	55 12%	97 14%	75 13%	31 11%	42 10%	37 11%	94 13%	115 11%	130 13%
6	(6) 123 6	69 % 7%	54 6%	11 4%	24 8%	18 6%	22 6%	23 7%	26 6%	49 7%	36 6%	14 5%	24 6%	25 7%	51 7%	51 5%	71 7%
5	(5) 132	63 % 6%	69 7%	26 11%fgh	30 10%fgh	24 7%	17 5%	14 4%	21 5%	45 6%	40 7%	17 6%	30 7%	23 7%	54 7%	70 7%	62 6%
4	(4) 24	13 %1%	10 1%	2 1%	4 1%	3 1%	3 1%	6 2%	6 1%	11 2%l	10 2%l	2 1%	1 *	7 2%n	4 1%	10 1%	14 1%
3	(3) 33	19 % 2%	14 1%	10 4%fg	5 2%	5 2%	3 1%	3 1%	8 2%	11 1%	11 2%	6 2%	6 1%	6 2%	9 1%	14 1%	19 2%
2	(2) 16	10 % 1%	6 1%	1 1%	4 1%	1 *	3 1%	5 2%	2 *	4 1%	6 1%	3 1%	3 1%	3 1%	9 1%	8 1%	8 1%
1	(1)	3 *	-	-	-	-	1 *	2 1%	-	2 *	1 *	-	-	1 *	1 *	3 *	-
Do not agree at all	(0) 14	9 % 1%	4	-	2 1%	3 1%	3 1%	4 1%	2 *	6 1%	3 1%	3 1%	2 *	2 *	8 1%	9 1%	5 *

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p



Absolutes/col percents

Page 11

Table 8

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

Patients should have access to a treatment based on clinical need, even if this would be individually costly to the NHS because of the rarity of a disease

		Ger	nder			Ag	e				Social	Grade		Employ Sec		Reg	gion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (o)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	1414	727	687	151	201	225	275	226	337	490	407	201	316	248	511	722	692
	71%	70%	71%	63%	65%	70%	76%cd	72%cd	74%cd	69%	69%	72%	75%i	70%	69%	72%	69%
NET: 4-7	523	269	254	80	97	89	76	73	108	201	161	65	97	92	203	246	277
	26%	26%	26%	33%fgh	31%fgh	28%f	21%	23%	24%	28%l	27%	23%	23%	26%	27%	25%	28%
NET: 0-3	66	41	25	11	11	8	11	13	12	22	21	12	11	12	27	34	32
	3%	4%	3%	4%	4%	3%	3%	4%	3%	3%	3%	4%	3%	3%	4%	3%	3%
Mean	8.16	8.11	8.21	7.82	7.95	8.15	8.32cd	8.17	8.33cd	8.08	8.04	8.29	8.36ij	8.10	8.08	8.19	8.13
Standard deviation	1.97	2.04	1.89	1.96	2.06	1.91	1.92	2.14	1.84	1.96	1.97	2.12	1.88	1.99	2.03	2.00	1.94
Standard error	0.04	0.06	0.06	0.14	0.12	0.10	0.10	0.12	0.09	0.07	0.08	0.13	0.09	0.11	0.08	0.06	0.06



Absolutes/col percents

Page 12

Table 9

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

The NHS should ensure that patients with very rare diseases have the same access to treatment as patients with common diseases, even if it means savings have to be made elsewhere in the NHS

			Ge	nder			Ag	e				Social G	arade		Employ Sect		Reg	ion
		Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base		2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base		2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely	(10)	680 34%	343 33%	336 35%	66 28%	100 32%	101 31%	134 37%c	111 36%	167 37%c	221 31%	177 30%	116 42%ij	165 39%ij	117 33%	248 33%	359 36%	320 32%
9	(9)	253 13%	123 12%	130 13%	28 12%	26 8%	38 12%	55 15%d	43 14%d	64 14%d	94 13%	70 12%	34 12%	55 13%	46 13%	85 12%	130 13%	124 12%
8	(8)	384 19%	201 19%	183 19%	42 18%	61 20%	64 20%	64 18%	64 21%	89 20%	141 20%k	125 21%k	38 14%	81 19%	62 18%	150 20%	178 18%	206 21%
7	(7)	257 13%	120 12%	138 14%	42 17%gh	46 15%g	44 14%	45 13%	28 9%	52 11%	92 13%	87 15%l	34 12%	45 11%	47 13%	98 13%	135 13%	122 12%
6	(6)	159 8%	94 9%	65 7%	27 11%f	29 9%f	28 9%	20 5%	22 7%	33 7%	59 8%	53 9%k	14 5%	33 8%	30 9%	60 8%	75 7%	84 8%
5	(5)	154 8%	78 7%	76 8%	20 8%	31 10%h	32 10%h	22 6%	22 7%	26 6%	50 7%	42 7%	30 11%	32 8%	28 8%	60 8%	76 8%	78 8%
4	(4)	47 2%	28 3%	19 2%	8 3%	7 2%	8 2%	5 1%	9 3%	11 2%	25 3%k	12 2%	3 1%	7 2%	12 3%	15 2%	12 1%	35 3%0
3	(3)	30 1%	20 2%	10 1%	3 1%	4 1%	3 1%	6 2%	6 2%	7 2%	13 2%	9 2%	4 2%	4 1%	8 2%n	5 1%	11 1%	19 2%
2	(2)	19 1%	16 2%b	3	3 1%	3 1%	1 *	4 1%	4 1%	4 1%	8 1%	9 1%	1 *	1 *	2 1%	8 1%	14 1%p	5 1%
1	(1)	6 *	6 1%b	-	-	1 *	2 1%	1 *	1 *	1 *	4 1%	2 *	-	-	1 *	3 *	4 *	2 *
Do not agree at all	(0)	13 1%	8 1%	4 *	2 1%	1 *	1 *	4 1%	2 1%	2 *	5 1%	3 1%	3 1%	1 *	-	7 1%	8 1%	5 1%



Absolutes/col percents

Page 13

Table 9

Q6. To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely? Base: All respondents

The NHS should ensure that patients with very rare diseases have the same access to treatment as patients with common diseases, even if it means savings have to be made elsewhere in the NHS

		Gen	der			Age					Social C	Grade		Employ Sec		Reg	jion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	1317	668	650	137	186	203	253	218	320	456	372	188	301	224	483	667	650
	66%	64%	67%	57%	60%	63%	70%cde	9 70%cd	70%cde	9 64%	63%	68%	71%ij	64%	65%	67%	65%
NET: 4-7	618	320	298	96	113	113	93	81	122	226	195	80	117	117	233	299	319
	31%	31%	31%	40%fgh	37%fgh	35%fgh	26%	26%	27%	32%	33%	29%	28%	33%	32%	30%	32%
NET: 0-3	68	50	18	8	9	7	16	13	15	31	23	9	6	11	24	37	31
	3%	5%b	2%	3%	3%	2%	4%	4%	3%	4%l	4%l	3%	1%	3%	3%	4%	3%
Mean	7.99	7.86	8.13a	7.68	7.83	7.89	8.15c	8.05	8.16cd	7.85	7.87	8.18ij	8.27ij	7.95	7.95	8.06	7.92
Standard deviation	2.07	2.20	1.90	2.09	2.05	2.01	2.12	2.13	2.00	2.16	2.05	2.12	1.86	2.03	2.10	2.08	2.05
Standard error	0.05	0.07	0.06	0.14	0.12	0.11	0.11	0.12	0.09	0.08	0.08	0.13	0.09	0.11	0.08	0.07	0.06



ONLINE Fieldwork: 28th April - 6th May 2014

Absolutes/col percents

Table 10

Q7. Given the state of NHS finances, the NHS might decide that a medicine, which it has been buying for years at the same price, is now "too expensive" to be provided by the NHS. The patients who have been taking the medicine would have no alternative treatment available. Should this be allowed? Base: All respondents

		Gen	der			Age					Social C	Grade		Employ Sect		Reg	lion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Yes	147 7%	95 9%b	52 5%	17 7%	32 10%h	21 7%	25 7%	25 8%	27 6%	54 8%l	53 9%l	23 8%l	17 4%	28 8%	64 9%	74 7%	73 7%
No	1699 85%	865 83%	835 86%	199 83%	245 79%	264 82%	319 88%de	271 87%d	401 88%de	614 86%	487 83%	237 85%	361 85%	294 83%	615 83%	856 85%	843 84%
Don't know	157 8%	78 7%	79 8%	25 10%fg	32 10%fgh	37 11%fgh	18 5%	16 5%	29 6%	44 6%	49 8%	18 7%	46 11%i	31 9%	61 8%	72 7%	85 8%



Absolutes/col percents

Table 11

Q8. Medicines are approved for use on a European basis by the European Medicines Agency. Should every EU country pay the same price for a particular medicine? Base: All respondents

		Gen	der			Aç	le				Social (Grade		Employ Sec		Rec	gion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Yes	1543 77%	786 76%	757 78%	186 77%	222 72%	242 75%	291 80%d	234 75%	369 81%dg	543 76%	446 76%	224 81%	329 78%	268 76%	560 76%	783 78%	760 76%
No	179 9%	118 11%b	61 6%	23 10%	34 11%	29 9%	26 7%	29 9%	36 8%	71 10%l	59 10%l	21 8%	27 6%	34 10%	77 10%	92 9%	86 9%
Don't know	281 14%	134 13%	147 15%	32 13%	53 17%h	51 16%	45 12%	49 16%	52 11%	98 14%	83 14%	32 12%	68 16%	50 14%	104 14%	127 13%	155 15%



ONLINE Fieldwork: 28th April - 6th May 2014

Absolutes/col percents

Page 16

Table 12

Q9. Do you think it is justified that a pharmaceutical company makes a profit on the drugs it has developed so that it can invest in the development of new medicines for the future?

Base: All respondents

		Gen	der			Age)				Social G	irade		Employ Sect		Reg	jion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Yes	1595 80%	867 84%b	728 75%	172 71%	226 73%	241 75%	296 82%cde	259 83%cde	401 88%cde	603 f 85%kl	477 81%kl	207 75%	307 72%	291 83%n	569 77%	805 80%	790 79%
No	236 12%	102 10%	134 14%a	44 18%fgh	43 14%gh	46 14%gh	43 12%	24 8%	36 8%	68 10%	62 10%	44 16%ij	62 15%ij	36 10%	105 14%	105 10%	131 13%
Don't know	173 9%	69 7%	103 11%a	26 11%h	39 13%fh	36 11%fh	23 6%	30 9%h	20 4%	41 6%	50 9%	26 9%i	55 13%ij	26 7%	66 9%	93 9%	80 8%



Absolutes/col percents

Table 13

Q10. What would you consider a "reasonable profit" for a company that researches, develops and manufactures medicines? Base: All respondents

			Ger	nder			Ag	e				Social	Grade			yment	Reç	
		Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base		2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base		2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
0%		17 1%	5 1%	12 1%	1 *	8 3%gh	2 1%	5 1%	1 *	1 *	5 1%	4 1%	4 1%	5 1%	2 1%	11 2%	7 1%	10 1%
5%		307 15%	168 16%	140 14%	43 18%g	55 18%g	63 20%fgh	50 14%	37 12%	59 13%	97 14%	95 16%	47 17%	68 16%	62 18%	109 15%	165 16%	142 14%
10%		730 36%	360 35%	369 38%	104 43%gh	133 43%gh	121 38%h	129 36%	107 34%	135 30%	256 36%	216 37%	102 37%	155 37%	133 38%	286 39%	371 37%	359 36%
15%		349 17%	183 18%	166 17%	40 17%	40 13%	45 14%	69 19%d	60 19%d	94 21%de	124 17%	99 17%	47 17%	78 18%	60 17%	126 17%	170 17%	179 18%
20%		465 23%	247 24%	218 23%	37 15%	55 18%	75 23%c	89 25%cd	81 26%cd	127 28%cd	177 25%	135 23%	62 22%	92 22%	85 24%	156 21%	225 22%	240 24%
More than 20%	(25)	135 7%	74 7%	60 6%	15 6%	17 6%	17 5%	19 5%	26 8%	40 9%	54 8%	39 7%	16 6%	26 6%	11 3%	52 7%m	64 6%	71 7%
Mean		13.35	13.48	13.21	12.37	12.13	12.76	13.40cd	14.21cd	14.47cd ef	13.73	13.25	12.97	13.09	12.77	13.13	13.16	13.54
Standard deviation Standard error		6.02 0.13	6.07 0.19	5.97 0.19	5.76 0.40	6.03 0.34	6.03 0.33	5.90 0.31	5.93 0.32	6.03 0.28	6.03 0.23	6.02 0.25	6.04 0.36	5.98 0.29	5.69 0.30	6.06 0.22	6.00 0.19	6.04 0.19

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p



ONLINE Fieldwork: 28th April - 6th May 2014

Absolutes/col percents

Table 14

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

- - ----

Summary table

		People with very rare diseases in Wales/ Scotland should have access to the same treatments and services as people in England	There should be a maximum price that the NHS will pay for treating people with very rare diseases	Funding for treatments for very rare diseases should be "ring- fenced" within the NHS budget	If the NHS has to cut costs in the future, it should start by no longer providing treatments for very rare diseases
Unweighted base		2003	2003	2003	2003
Weighted base		2003	2003	2003	2003
Agree entirely	(10)	1250 62%	105 5%	267 13%	28 1%
9	(9)	242 12%	60 3%	135 7%	15 1%
8	(8)	196 10%	166 8%	236 12%	54 3%
7	(7)	92 5%	188 9%	225 11%	72 4%
6	(6)	67 3%	150 8%	194 10%	79 4%
5	(5)	104 5%	348 17%	487 24%	235 12%
4	(4)	14 1%	109 5%	85 4%	114 6%
3	(3)	14 1%	155 8%	95 5%	191 10%
2	(2)	8 *	171 9%	90 4%	266 13%
1	(1)	5 *	153 8%	59 3%	238 12%
Do not agree at all	(0)	12 1%	397 20%	131 7%	712 36%



ONLINE Fieldwork: 28th April - 6th May 2014

Absolutes/col percents

Page 19

Table 14

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of the second statements of the second statements of the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree here the second statements of 0 to 10 where 0 means you agree with the second statements of 0 to 10 where 0 means you do not agree at all and 10 means you agree with the second statements of 0 to 10 where 0 means you agree with the second statements of 0 to 10 where 0 means you agree with the second statements of 0 to 10 where 0 means you agree with the second statement with the s

Base: All respondents

Summary table

	People with very rare diseases in Wales/ Scotland should have access to the same treatments and services as people in England	There should be a maximum price that the NHS will pay for treating people with very rare diseases	Funding for treatments for very rare diseases should be "ring- fenced" within the NHS budget	If the NHS has to cut costs in the future, it should start by no longer providing treatments for very rare diseases
Weighted base	2003	2003	2003	2003
NET: 8-10	1687	330	638	97
	84%	16%	32%	5%
NET: 4-7	276	796	991	500
	14%	40%	49%	25%
NET: 0-3	39	877	374	1407
	2%	44%	19%	70%
Mean	8.95	4.13	5.89	2.39
Standard deviation	1.82	3.09	2.82	2.55
Standard error	0.04	0.07	0.06	0.06

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Absolutes/col percents

Table 15

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

People with very rare diseases in Wales/ Scotland should have access to the same treatments and services as people in England

			Gen	ıder			Ag	e				Social C	Grade		Employ Sec	tor	Regi	
	-	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely	(10)	1250 62%	617 59%	633 66%a	144 60%	185 60%	186 58%	232 64%	199 64%	304 67%e	422 59%	357 61%	186 67%i	285 67%ij	216 61%	450 61%	657 66%p	593 59%
9	(9)	242 12%	139 13%	103 11%	18 8%	33 11%	48 15%c	51 14%c	37 12%	54 12%	89 13%	78 13%	28 10%	45 11%	53 15%	93 13%	116 12%	126 13%
8	(8)	196 10%	99 10%	97 10%	24 10%	21 7%	40 12%d	32 9%	35 11%d	44 10%	84 12%kl	63 11%l	21 7%	28 7%	28 8%	77 10%	88 9%	108 11%
7	(7)	92 5%	49 5%	43 4%	16 7%	21 7%g	12 4%	16 4%	10 3%	18 4%	30 4%	29 5%	16 6%	17 4%	12 3%	37 5%	52 5%	40 4%
6	(6)	67 3%	44 4%b	23 2%	13 6%f	17 5%fg	10 3%	6 2%	8 2%	13 3%	30 4%	17 3%	7 3%	13 3%	14 4%	25 3%	27 3%	39 4%
5	(5)	104 5%	56 5%	47 5%	20 8%fh	29 9%fgh	18 6%h	12 3%	14 4%	11 2%	32 4%	31 5%	12 4%	29 7%	23 7%	37 5%	44 4%	60 6%
4	(4)	14 1%	7 1%	7 1%	-	-	3 1%	4 1%	5 1%d	2 *	4 1%	4 1%	3 1%	3 1%	3 1%	8 1%	4 *	10 1%
3	(3)	14 1%	11 1%b	3 *	5 2%g	1 *	2 1%	2 1%	1 *	3 1%	6 1%l	5 1%	3 1%l	-	1 *	3 *	3 *	11 1%o
2	(2)	8 *	3 *	5 1%	1 1%	1 *	-	1 *	-	5 1%	5 1%	2 *	-	1 *	-	1 *	2 *	6 1%
1	(1)	5 *	2 *	3 *	-	-	1 *	2 1%	1 *	1 *	2 *	1 *	1 *	1 *	-	2 *	3 *	2
Do not agree at all	(0)	12 1%	10 1%b	2 *	-	1 *	3 1%	3 1%	3 1%	2 *	8 1%	2 *	-	2 *	1 *	8 1%	6 1%	6 1%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

Prepared by Populus Commissioned and funded by Genzyme Therapeutics Limited



Absolutes/col percents

Page 21

Table 15

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

People with very rare diseases in Wales/ Scotland should have access to the same treatments and services as people in England

		Gen	ider		Age							Grade		Employ Sec	tor	Regi	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	1687	855	833	186	239	274	315	271	403	595	498	235	359	298	619	861	827
	84%	82%	86%a	77%	78%	85%cd	87%cd	87%cd	88%cd	84%	85%	85%	85%	85%	84%	86%p	83%
NET: 4-7	276	157	120	49	66	43	38	36	44	95	81	38	62	52	107	127	149
	14%	15%	12%	20%efg	h 21%efgh	1 13%	11%	12%	10%	13%	14%	14%	15%	15%	14%	13%	15%
NET: 0-3	39	27	13	6	3	6	8	5	11	22	10	4	4	2	14	14	25
	2%	3%b	1%	3%	1%	2%	2%	2%	2%	3%l	2%	1%	1%	1%	2%	1%	3%
Mean	8.95	8.83	9.07a	8.70	8.79	8.88	9.04c	9.01	9.12cd	8.83	8.95	9.08	9.05	9.00	8.89	9.08p	8.82
Standard deviation	1.82	1.93	1.68	1.93	1.85	1.84	1.82	1.81	1.70	1.97	1.74	1.67	1.75	1.67	1.89	1.70	1.92
Standard error	0.04	0.06	0.05	0.13	0.11	0.10	0.10	0.10	0.08	0.07	0.07	0.10	0.08	0.09	0.07	0.05	0.06



Absolutes/col percents

Table 16

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

There should be a maximum price that the NHS will pay for treating people with very rare diseases

			Gen	der			Age	9				Social (Grade		Employ Sec	tor	Reg	
		Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base		2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base		2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely	(10)	105 5%	64 6%b	41 4%	7 3%	14 5%	11 3%	27 7%ce	17 5%	29 6%	24 3%	33 6%	15 5%	32 8%i	14 4%	33 4%	53 5%	52 5%
9	(9)	60 3%	30 3%	30 3%	8 3%	5 2%	9 3%	9 2%	10 3%	19 4%	19 3%	21 4%	9 3%	11 3%	8 2%	20 3%	31 3%	29 3%
8	(8)	166 8%	101 10%b	64 7%	21 9%	32 10%f	21 7%	21 6%	22 7%	48 11%f	74 10%jk	43 7%	15 5%	33 8%	23 7%	65 9%	83 8%	82 8%
7	(7)	188 9%	115 11%b	73 8%	21 9%	24 8%	41 13%df	22 6%	29 9%	51 11%f	65 9%	59 10%	28 10%	37 9%	31 9%	71 10%	78 8%	109 11%o
6	(6)	150 8%	78 8%	72 7%	18 8%	28 9%	24 8%	25 7%	24 8%	30 7%	59 8%	50 9%	17 6%	25 6%	27 8%	63 8%	81 8%	70 7%
5	(5)	348 17%	174 17%	174 18%	50 21%h	69 23%fh	61 19%	52 14%	52 17%	64 14%	117 16%	102 17%	51 18%	79 19%	66 19%	118 16%	166 17%	182 18%
4	(4)	109 5%	46 4%	63 7%a	19 8%	19 6%	17 5%	19 5%	15 5%	21 5%	38 5%	37 6%	12 4%	23 5%	22 6%	40 5%	51 5%	59 6%
3	(3)	155 8%	70 7%	86 9%	28 11%	21 7%	23 7%	28 8%	23 7%	32 7%	62 9%	45 8%	14 5%	35 8%	26 7%	55 7%	87 9%	68 7%
2	(2)	171 9%	84 8%	87 9%	26 11%	22 7%	32 10%	31 8%	20 6%	41 9%	60 8%	62 11%l	20 7%	29 7%	38 11%	64 9%	85 8%	86 9%
1	(1)	153 8%	75 7%	78 8%	10 4%	21 7%	26 8%	43 12%cdg	21 h 7%	31 7%	67 9%	38 6%	19 7%	29 7%	40 11%	61 8%	78 8%	75 8%
Do not agree at all	(0)	397 20%	200 19%	198 20%	33 14%	51 17%	57 18%	85 24%cd	79 25%cde	91 20%	128 18%	99 17%	78 28%ijl	92 22%	56 16%	153 21%	209 21%	188 19%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

Prepared by Populus Commissioned and funded by Genzyme Therapeutics Limited



ONLINE Fieldwork: 28th April - 6th May 2014

Table 16

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50.000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

There should be a maximum price that the NHS will pay for treating people with very rare diseases

		Gen	der			Age	Э				Social	Grade		Employ Sec		Rec	gion
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	330	196	135	36	52	41	57	49	96	117	97	39	77	45	118	168	163
	16%	19%b	14%	15%	17%	13%	16%	16%	21%e	16%	17%	14%	18%	13%	16%	17%	16%
NET: 4-7	796	413	383	108	141	144	118	120	166	278	247	107	163	146	291	375	420
	40%	40%	40%	45%fh	46%fh	45%fh	33%	38%	36%	39%	42%	39%	38%	42%	39%	37%	42%o
NET: 0-3	877	429	448	97	116	138	187	143	195	317	244	131	184	161	332	459	418
	44%	41%	46%a	40%	38%	43%	52%c	deh 46%d	43%	44%	42%	47%	43%	46%	45%	46%	42%
Mean	4.13	4.34b	3.90	4.31f	4.33f	4.10	3.71	3.96	4.36f	4.10	4.30k	3.78	4.18	3.95	4.05	4.04	4.22
Standard deviation	3.09	3.16	2.99	2.77	2.93	2.93	3.22	3.20	3.24	3.00	3.03	3.23	3.21	2.91	3.08	3.11	3.07
Standard error	0.07	0.10	0.09	0.19	0.17	0.16	0.17	0.17	0.15	0.11	0.13	0.19	0.15	0.15	0.11	0.10	0.10

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p



Page 23

Absolutes/col percents

Absolutes/col percents

Table 17

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

Funding for treatments for very rare diseases should be "ring-fenced" within the NHS budget

		Ge	nder	Age							Social (Grade		Employ Sect	or	Reg	ion
	Tota	al Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Unweighted base	2003	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely	(10) 267 13		107 0 11%	12 5%	22 7%	31 10%	55 15%cde	61 e 19%cde	87 9%cde	100 14%	71 12%	40 14%	57 13%	41 12%	76 10%	140 14%	127 13%
9	(9) 135 7	73 % 7%	62 6%	6 3%	11 3%	21 6%c	25 7%c	23 7%cd	49 11%cde	52 7%	39 7%	14 5%	29 7%	26 7%	45 6%	63 6%	71 7%
8	(8) 236 12		112 12%	15 6%	37 12%c	38 12%c	38 10%	49 16%cf	60 13%c	94 13%	65 11%	36 13%	40 9%	42 12%	92 12%	117 12%	119 12%
7	(7) 225 11		98 10%	27 11%	43 14%	33 10%	38 11%	33 11%	50 11%	81 11%	78 13%	27 10%	39 9%	38 11%	88 12%	103 10%	122 12%
6	(6) 194 10		92 10%	29 12%	32 10%	39 12%	30 8%	28 9%	36 8%	66 9%	56 10%	30 11%	41 10%	37 10%	75 10%	109 11%	85 8%
5	(5) 487 24		273 28%a	89 37%defç h	85 g 27%fgh	88 27%fgh	74 1 21%	65 21%	86 19%	151 21%	138 23%	61 22%	137 32%ijk	78 x 22%	180 24%	236 24%	251 25%
4	(4) 85 4	38 % 4%	47 5%	14 6%	18 6%g	17 5%	15 4%	7 2%	15 3%	30 4%	29 5%	11 4%	16 4%	15 4%	34 5%	42 4%	43 4%
3	(3) 95 5	51 % 5%	43 4%	20 8%eg	16 5%	8 2%	16 4%	11 4%	24 5%e	40 6%l	31 5%	11 4%	13 3%	24 7%n	30 4%	53 5%	41 4%
2	(2) 90 4	45 % 4%	44 5%	16 7%h	15 5%	14 4%	21 6%	10 3%	14 3%	30 4%	32 5%	11 4%	16 4%	20 6%	34 5%	41 4%	49 5%
1	(1) 59 3	34 % 3%	25 3%	4 1%	5 2%	13 4%	19 5%cdg	7 g 2%	12 3%	29 4%l	15 3%	8 3%	8 2%	12 3%	29 4%	30 3%	29 3%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

Prepared by Populus Commissioned and funded by Genzyme Therapeutics Limited



ONLINE Fieldwork: 28th April - 6th May 2014

Table 17

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

Funding for treatments for very rare diseases should be "ring-fenced" within the NHS budget

															Employ	/ment		
			Ge	ender	Age							Social C	Grade		Sec	tor	Region	
		Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (o)	Scot- land (p)
Weighted base		2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Do not agree at all	(0)	131 7%	69 7%	62 6%	9 4%	25 8%c	22 7%	32 9%c	19 6%	25 5%	40 6%	35 6%	29 10%ij	28 7%	19 5%	58 8%	69 7%	62 6%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

Page 25

Absolutes/col percents

Absolutes/col percents

Page 26

Table 17

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

Funding for treatments for very rare diseases should be "ring-fenced" within the NHS budget

		Gen	der			Age					Social (Grade		Employ Sec		Region	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)		55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	638	357	281	34	69	90	117	133	195	246	175	91	126	109	213	320	318
	32%	34%b	29%	14%	23%c	28%c	32%cd	43%cde	f 43%cde	f 34%	30%	33%	30%	31%	29%	32%	32%
NET: 4-7	991	481	510	159	178	176	157	133	187	328	300	128	234	169	377	490	501
	49%	46%	53%a	66%efgl	n 58%fgh	55%fgh	44%	43%	41%	46%	51%	46%	55%ik	48%	51%	49%	50%
NET: 0-3	374	200	174	48	61	56	87	47	75	138	113	58	65	75	150	193	182
	19%	19%	18%	20%	20%	18%	24%egh	15%	16%	19%	19%	21%	15%	21%	20%	19%	18%
Mean	5.89	6.02b	5.76	5.23	5.46	5.69c	5.68	6.46cde f	6.46cde	5.99	5.84	5.76	5.90	5.80	5.66	5.88	5.91
Standard deviation	2.82	2.90	2.73	2.22	2.62	2.73	3.11	2.86	2.88	2.85	2.76	3.03	2.72	2.78	2.83	2.85	2.80
Standard error	0.06	0.09	0.09	0.15	0.15	0.15	0.17	0.16	0.13	0.11	0.11	0.18	0.13	0.15	0.10	0.09	0.09



Absolutes/col percents

Table 18

Q11. In general, because of the large costs of development, the rarer the disease the higher the price for new treatments which aim to improve both life expectancy and clinical outcomes for patients with that disease. Very rare diseases tend to affect about one in 50,000 individuals (about 60 people in Wales/ about 100 people in Scotland). To what extent do you agree with the following statements on a scale of 0 to 10 where 0 means you do not agree at all and 10 means you agree entirely?

Base: All respondents

If the NHS has to cut costs in the future, it should start by no longer providing treatments for very rare diseases

		G	ender			Ag	e			Social Grade				Employment <u>Sector</u> Pri-		Region	
	To	tal Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (l)	Public (m)	vate (n)	Wales (o)	Scot- land (p)
Unweighted base	200	995	1008	208	310	332	354	339	460	714	581	279	429	357	731	1002	1001
Weighted base	200	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
Agree entirely		28 20 1% 2%	8 5b 1%	3 1%	2 1%	8 2%	6 2%	4 1%	5 1%	8 1%	11 2%	7 3%l	2 *	2 1%	15 2%	21 2%p	7 1%
9		5 12 1% 1%	3 56 *	3 1%	-	4 1%	2 1%	3 1%	3 1%	4 1%	6 1%	2 1%	2 *	1 *	3 *	8 1%	7 1%
8	(8) 5	54 37 3% 4%	17 b 2%	6 2%	10 3%	6 2%	11 3%	11 4%	10 2%	23 3%	17 3%	5 2%	9 2%	12 3%	20 3%	27 3%	27 3%
7		'2 41 4% 4%	31 5 3%	8 3%	18 6%g	12 4%	12 3%	8 3%	14 3%	28 4%	20 3%	7 3%	17 4%	4 1%	39 5%m	39 4%	33 3%
6		'9 44 4% 4%	35 5 4%	9 4%	18 6%	12 4%	13 4%	11 4%	15 3%	24 3%	25 4%	9 3%	21 5%	16 5%	29 4%	38 4%	41 4%
5	(5) 23 1	85 131 2% 13%	104 5 11%	30 13%	44 14%	41 13%	35 10%	35 11%	49 11%	89 12%	69 12%	26 9%	52 12%	39 11%	79 11%	112 11%	123 12%
4	(4) 11	4 50 6% 5%	64 5 7%	15 6%	28 9%efg	12 4%	16 5%	16 5%	27 6%	45 6%	33 6%	19 7%	17 4%	25 7%	41 6%	53 5%	61 6%
3	(3) 19 1	01 93 0% 9%	98 5 10%	25 10%	23 8%	39 12%f	24 7%	29 9%	51 11%f	74 10%	59 10%	18 6%	41 10%	31 9%	67 9%	98 10%	93 9%
2	(2) 26 1	6 132 3% 13%	134 5 14%	45 19%fh	38 12%	46 14%	43 12%	44 14%	50 11%	89 13%	96 16%l	32 11%	49 12%	55 16%	100 14%	123 12%	143 14%
1	(1) 23 1	88 113 2% 119	125 5 13%	21 9%	35 11%	41 13%	56 16%cg	30 10%	55 12%	101 14%	62 10%	28 10%	47 11%	53 15%	90 12%	123 12%	115 11%
Do not agree at all	(0) 71 3	2 365 36% 35%	347 5 36%	76 32%	91 30%	102 32%	143 40%de	121 39%d	178 39%de	226 32%	193 33%	125 45%ij	168 40%ij	113 32%	257 35%	361 36%	351 35%

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p

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ONLINE Fieldwork: 28th April - 6th May 2014

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Base: All respondents

If the NHS has to cut costs in the future, it should start by no longer providing treatments for very rare diseases

		Gen	der			Ag	е				Social (Grade		Employ Sec		Region	
	Total	Male (a)	Female (b)	18-24 (c)	25-34 (d)	35-44 (e)	45-54 (f)	55-64 (g)	65+ (h)	AB (i)	C1 (j)	C2 (k)	DE (I)	Public (m)	Pri- vate (n)	Wales (0)	Scot- land (p)
Weighted base	2003	1038	965	241	308	322	362	312	457	712	589	277	424	352	740	1002	1001
NET: 8-10	97 5%	69 7%b	28 3%	12 5%	12 4%	18 5%	19 5%	17 6%	18 4%	36 5%	34 6%l	14 5%	13 3%	15 4%	38 5%	55 6%	41 4%
NET: 4-7	500 25%	266 26%	234 24%	63 26%	108 35%ce h	78 fg 24%	76 21%	70 22%	105 23%	186 26%	146 25%	60 22%	107 25%	85 24%	188 25%	242 24%	258 26%
NET: 0-3	1407 70%	703 68%	704 73%a	167 69%	188 61%	227 70%d	266 74%d	225 72%d	334 73%d	490 69%	409 69%	203 73%	304 72%	252 72%	514 69%	705 70%	702 70%
Mean	2.39	2.57b	2.21	2.55	2.76fgh	2.55	2.16	2.30	2.20	2.49k	2.53k	2.10	2.24	2.29	2.48	2.42	2.36
Standard deviation Standard error	2.55 0.06	2.71 0.09	2.36 0.07	2.51 0.17	2.55 0.14	2.62 0.14	2.59 0.14	2.56 0.14	2.47 0.12	2.53 0.09	2.60 0.11	2.63 0.16	2.47 0.12	2.35 0.12	2.64 0.10	2.64 0.08	2.47 0.08

Proportions/Means: Columns Tested (5% risk level) - a/b - c/d/e/f/g/h - i/j/k/l - m/n - o/p



Page 28

Absolutes/col percents