Appendix 1 – NRAS Survey

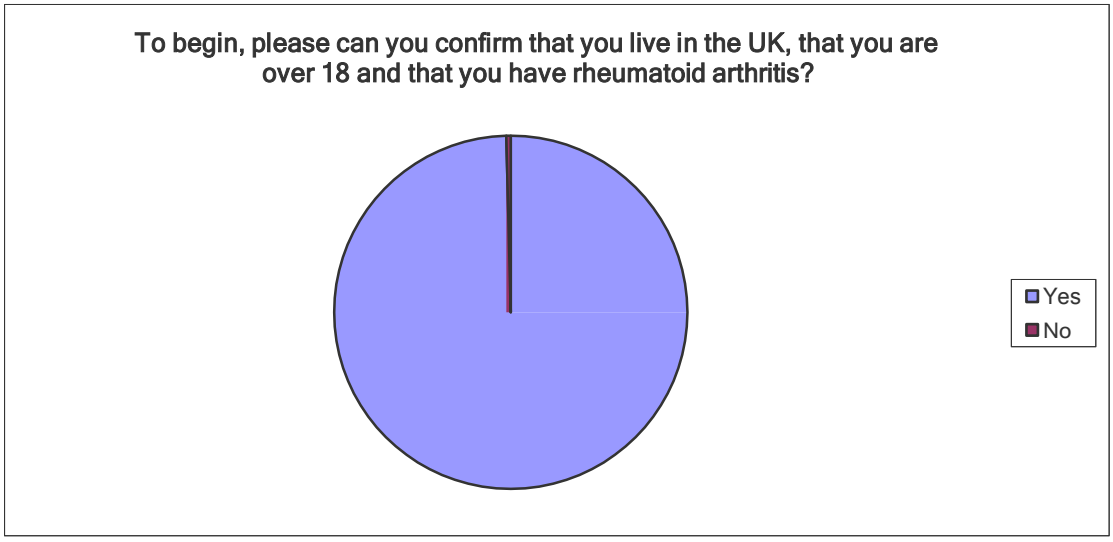
Appendix 1 forms part of the NRAS Response to DSU Report and Assessment Report relating to the Multiple Technology Appraisal (MTA) Adalimumab, etanercept, infliximab, certolizumab pegol, golimumab, abatacept and tocilizumab for the treatment of rheumatoid arthritis (review of TA guidance 130, 186, 224, 234 and part review of TA guidance 225 and 247) [ID537]

- **NRAS survey sent out via website, Facebook, HealthUnlocked, Twitter, Members' e-news**
- **Survey ran from Friday 20th March to Friday 27th March**
- **Total questionnaires returned: 1,016**
- **Total participants meeting the criteria to take part: 1,009**
- **Participants were mix of members and non-members of NRAS**
- **Total questionnaires meeting the criteria and with all questions completed: 850**

1st April, 2015

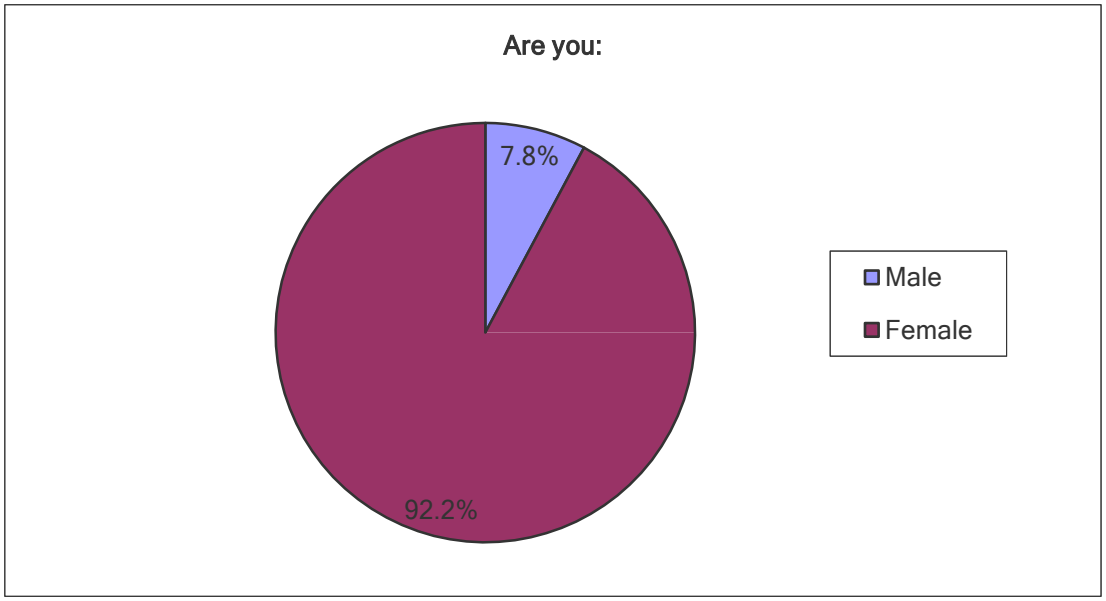
NICE review of RA drugs

To begin, please can you confirm that you live in the UK, that you are over 18 and that you have rheumatoid arthritis?		
Answer Options	Response Percent	Response Count
Yes	99.6%	854
No	0.4%	3
	answered question	857
	skipped question	0



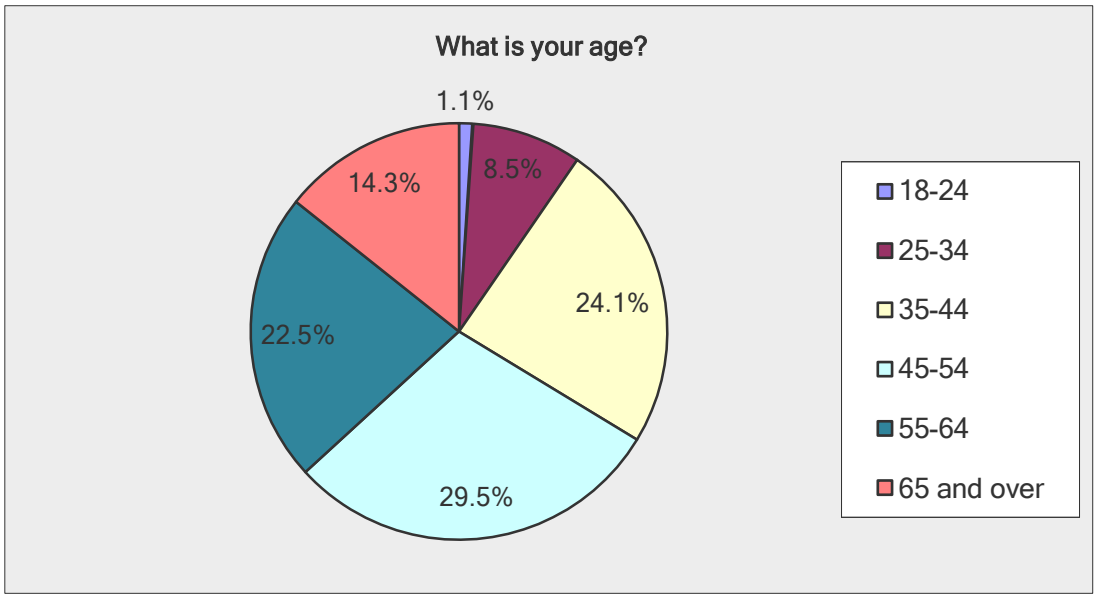
NICE review of RA drugs

Are you:		
Answer Options	**Response Percent**	**Response Count**
Male	7.8%	67
Female	92.2%	787
	answered question	854
	skipped question	3



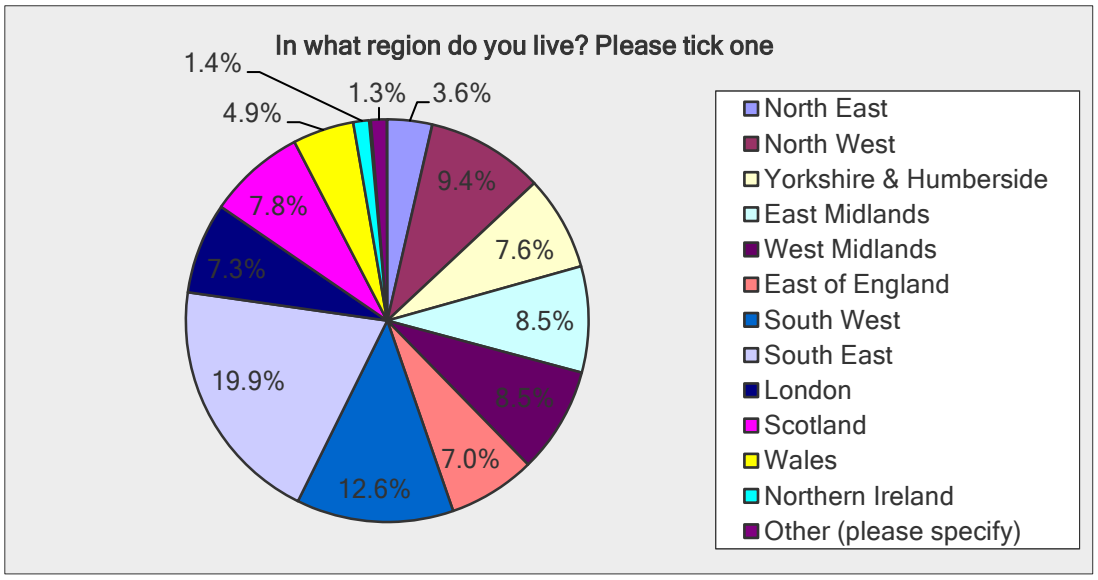
NICE review of RA drugs

What is your age?		
Answer Options	Response Percent	Response Count
18-24	1.1%	9
25-34	8.5%	73
35-44	24.1%	206
45-54	29.5%	252
55-64	22.5%	192
65 and over	14.3%	122
	answered question	854
	skipped question	3



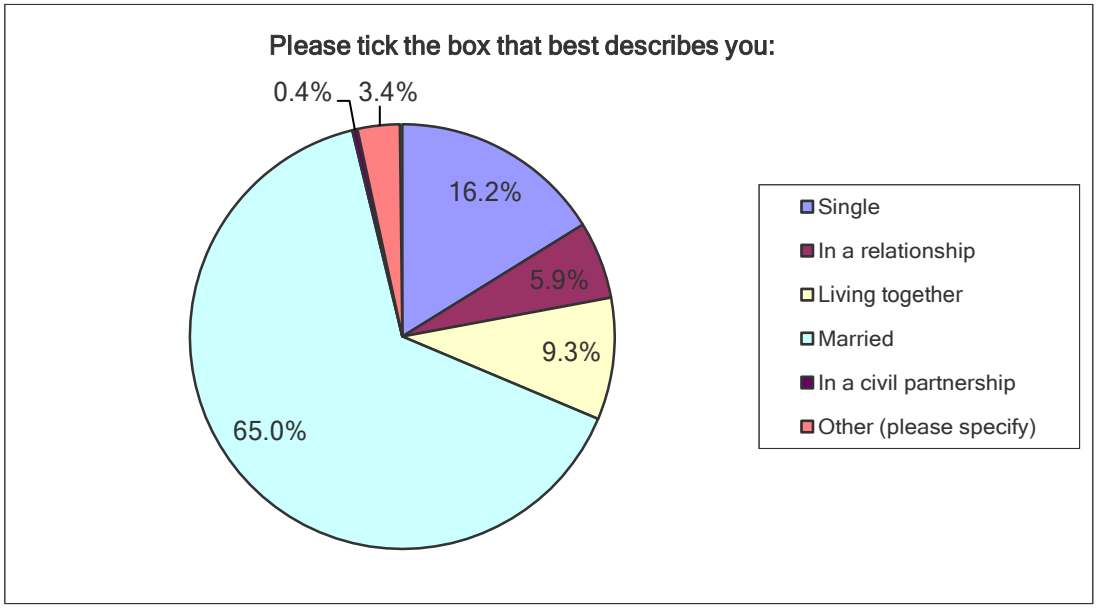
NICE review of RA drugs

In what region do you live? Please tick one		
Answer Options	**Response Percent**	**Response Count**
North East	3.6%	31
North West	9.4%	80
Yorkshire & Humberside	7.6%	65
East Midlands	8.5%	73
West Midlands	8.5%	73
East of England	7.0%	60
South West	12.6%	108
South East	19.9%	170
London	7.3%	62
Scotland	7.8%	67
Wales	4.9%	42
Northern Ireland	1.4%	12
Other (please specify)	1.3%	11
	answered question	**854**
	skipped question	**3**



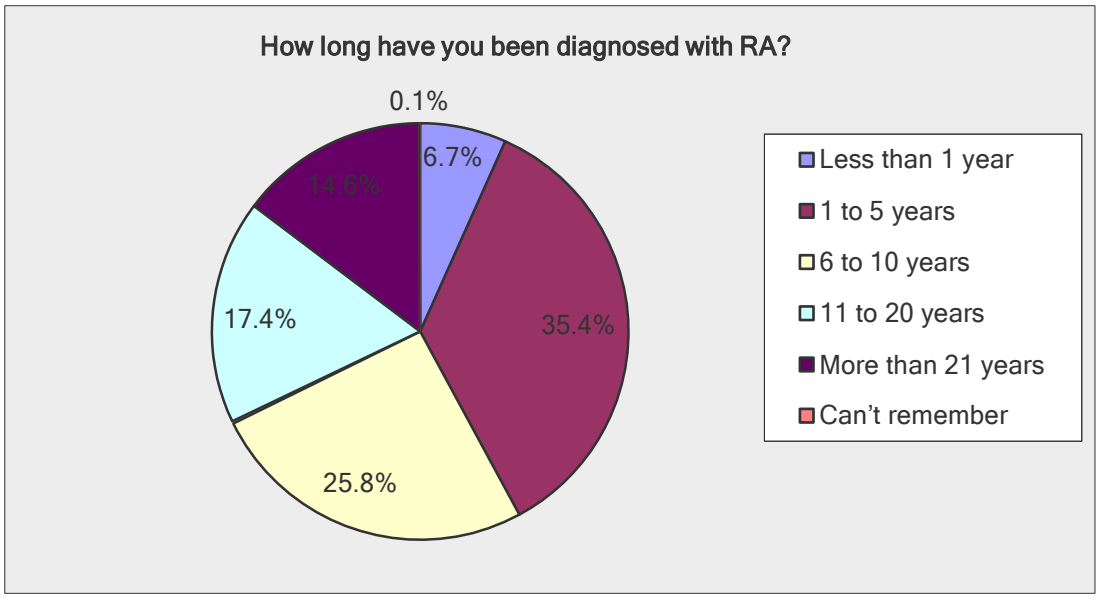
NICE review of RA drugs

Please tick the box that best describes you:		
Answer Options	**Response Percent**	**Response Count**
Single	16.2%	138
In a relationship	5.9%	50
Living together	9.3%	79
Married	65.0%	555
In a civil partnership	0.4%	3
Other (please specify)	3.4%	29
	answered question	854
	skipped question	3



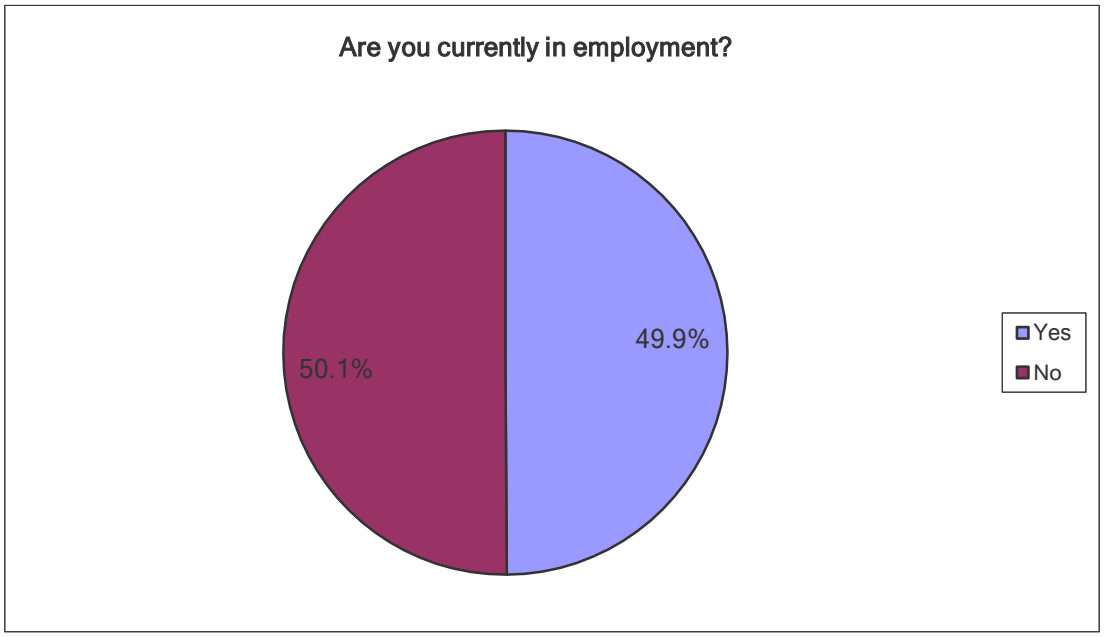
NICE review of RA drugs

How long have you been diagnosed with RA?		
Answer Options	**Response Percent**	**Response Count**
Less than 1 year	6.7%	57
1 to 5 years	35.4%	302
6 to 10 years	25.8%	220
11 to 20 years	17.4%	149
More than 21 years	14.6%	125
Can't remember	0.1%	1
	answered question	854
	skipped question	3



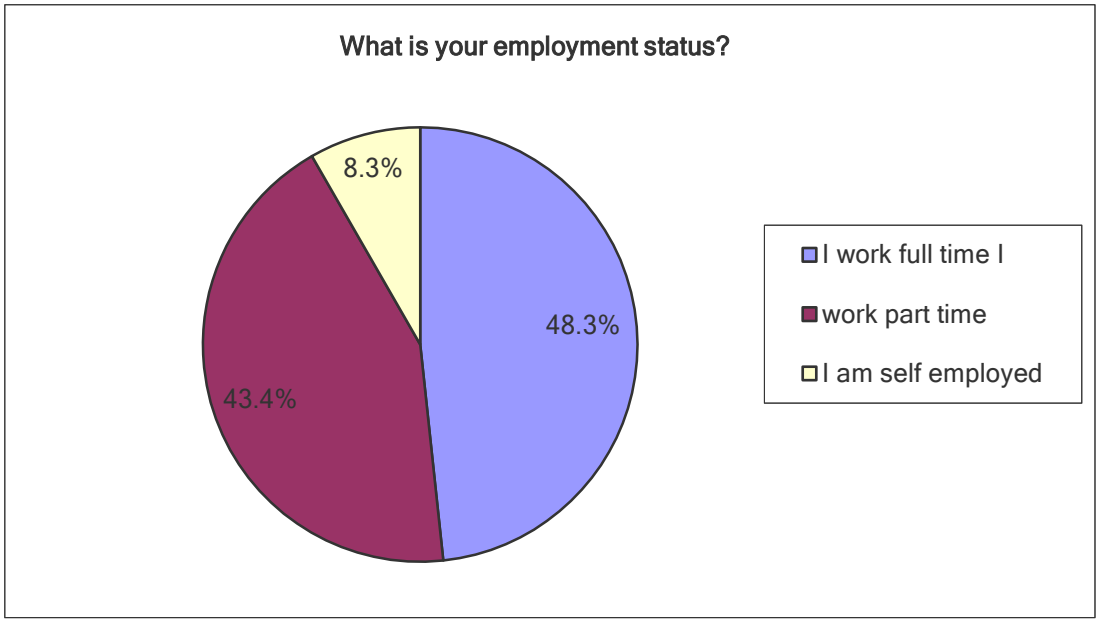
NICE review of RA drugs

Are you currently in employment?		
Answer Options	Response Percent	Response Count
Yes	49.9%	425
No	50.1%	427
	answered question	852
	skipped question	5



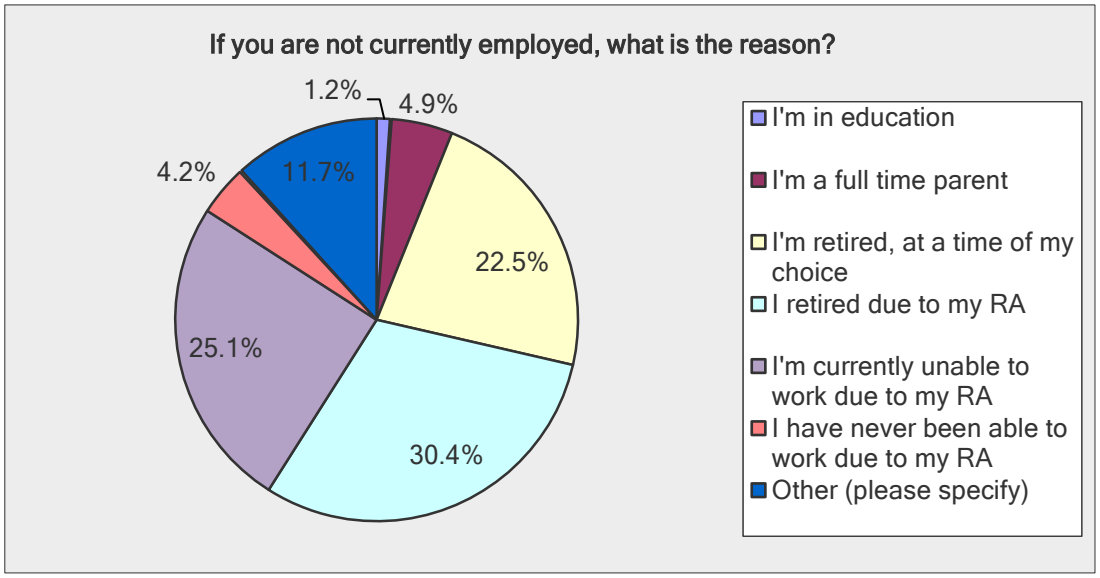
NICE review of RA drugs

What is your employment status?		
Answer Options	Response Percent	Response Count
I work full time	48.3%	204
I work part time	43.4%	183
I am self employed	8.3%	35
	answered question	422
	skipped question	435



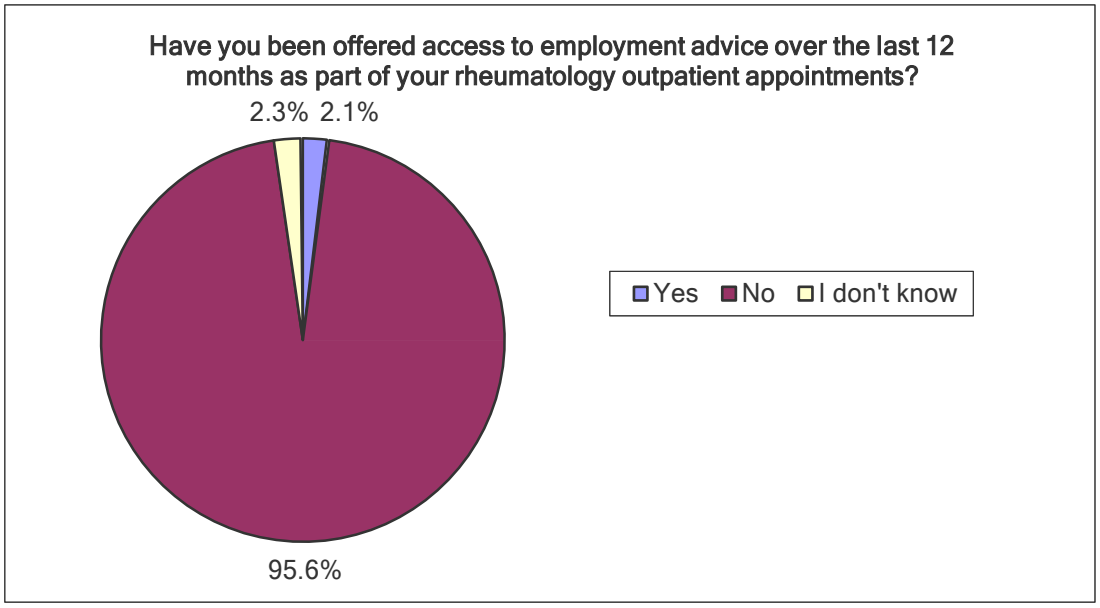
NICE review of RA drugs

If you are not currently employed, what is the reason?		
Answer Options	**Response Percent**	**Response Count**
I'm in education	1.2%	5
I'm a full time parent	4.9%	21
I'm retired, at a time of my choice	22.5%	96
I retired due to my RA	30.4%	130
I'm currently unable to work due to my RA	25.1%	107
I have never been able to work due to my RA	4.2%	18
Other (please specify)	11.7%	50
	answered question	427
	skipped question	430



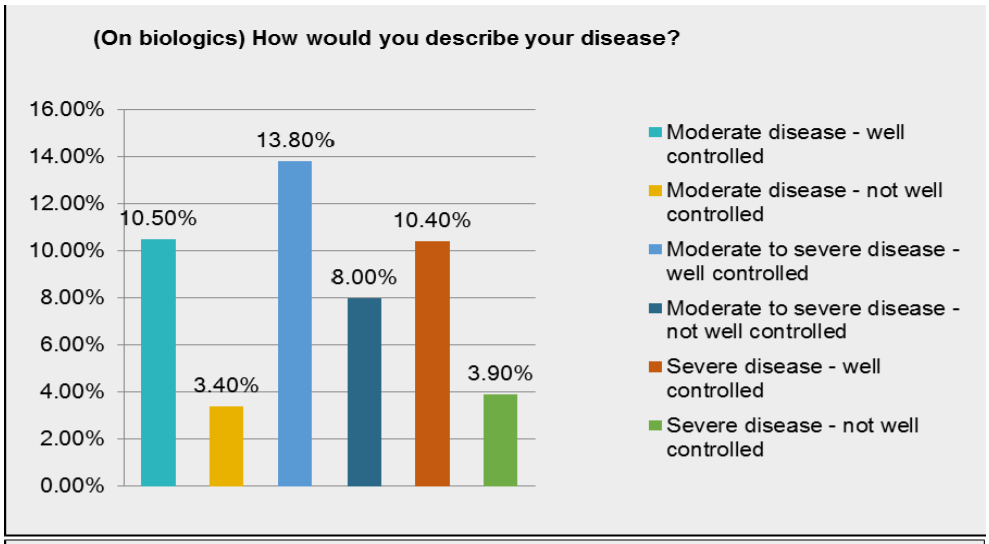
NICE review of RA drugs

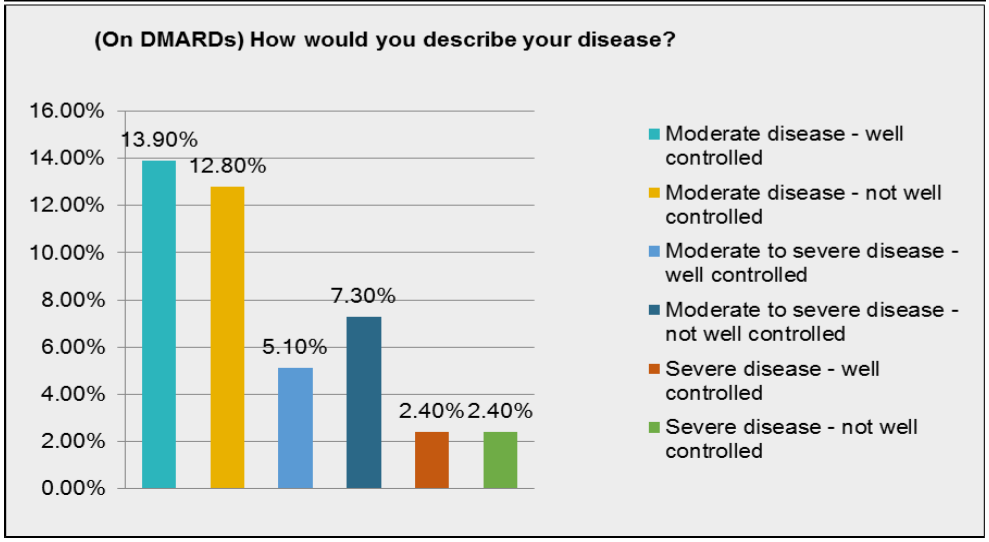
Have you been offered access to employment advice over the last 12 months as part of your rheumatology outpatient appointments?		
Answer Options	**Response Percent**	**Response Count**
Yes	2.1%	18
No	95.6%	806
I don't know	2.3%	19
	answered question	**843**
	skipped question	**14**



NICE review of RA drugs

How would you describe your disease?		
Answer Options	**Response Percent**	**Response Count**
Moderate disease - well controlled by DMARDs	13.9%	118
Moderate disease - not well controlled by DMARDs	12.8%	108
Moderate disease - well controlled by biologics (with or	10.5%	89
Moderate disease - not well controlled by biologics (with	3.4%	29
Moderate to severe disease - well controlled by DMARDs	5.1%	43
Moderate to severe disease - not well controlled by	7.3%	62
Moderate to severe disease - well controlled by biologics	13.8%	117
Moderate to severe disease - not well controlled by	8.0%	68
Severe disease - well controlled by DMARDs	2.4%	20
Severe disease - not well controlled by DMARDs	2.4%	20
Severe disease - well controlled by biologics (with or	10.4%	88
Severe disease - not well controlled by biologics (with or	3.9%	33
Other (please specify)	6.0%	51
	answered question	846
	skipped question	11

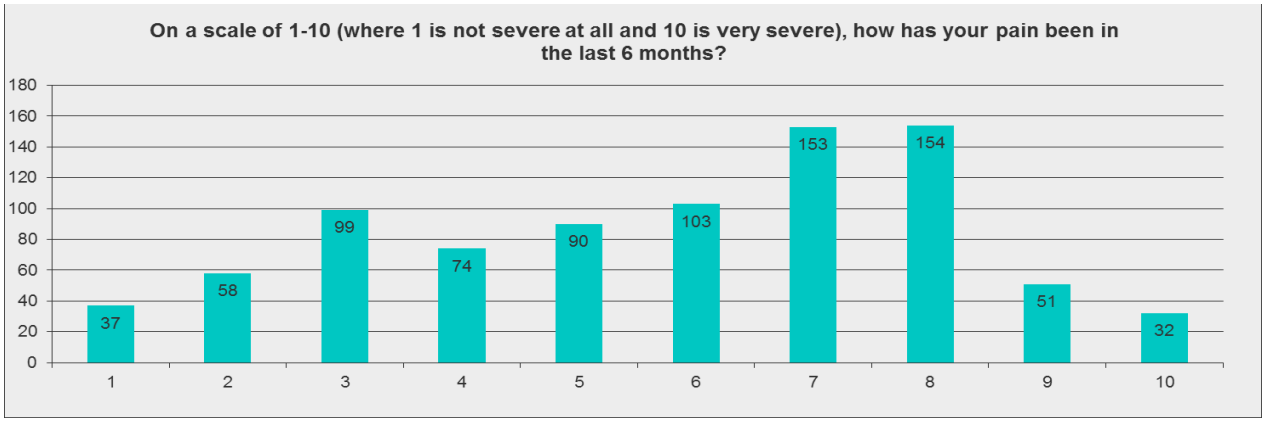




NICE review of RA drugs

On a scale of 1-10 (where 1 is not severe at all and 10 is very severe), how has your pain been in the last6 months?

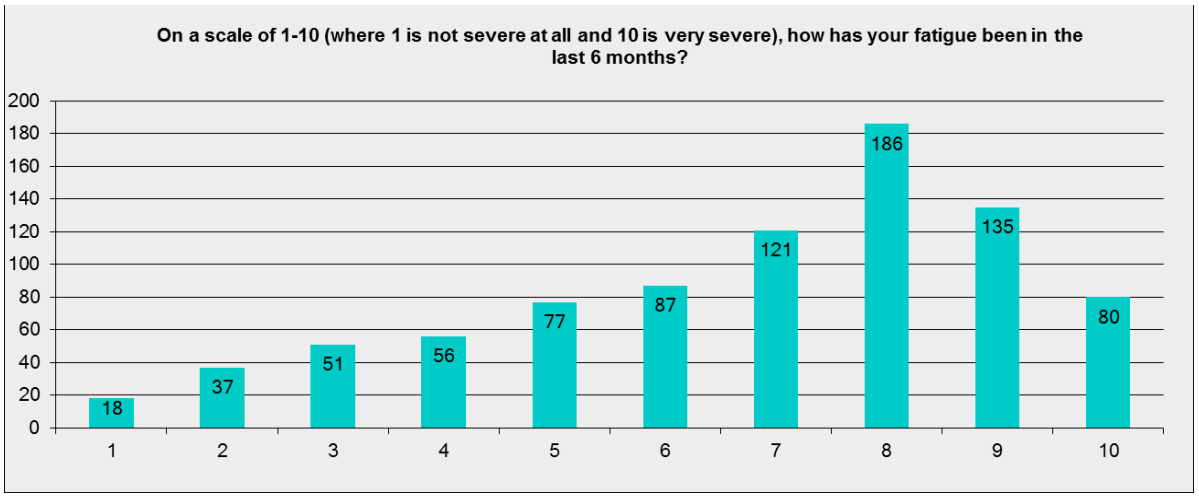
Answer Options	1	2	3	4	5	6	7	8	9	10	Rating Average	Response Count
	37	58	99	74	90	103	153	154	51	32	5.75	851
											answered question	851
											skipped question	6



NICE review of RA drugs

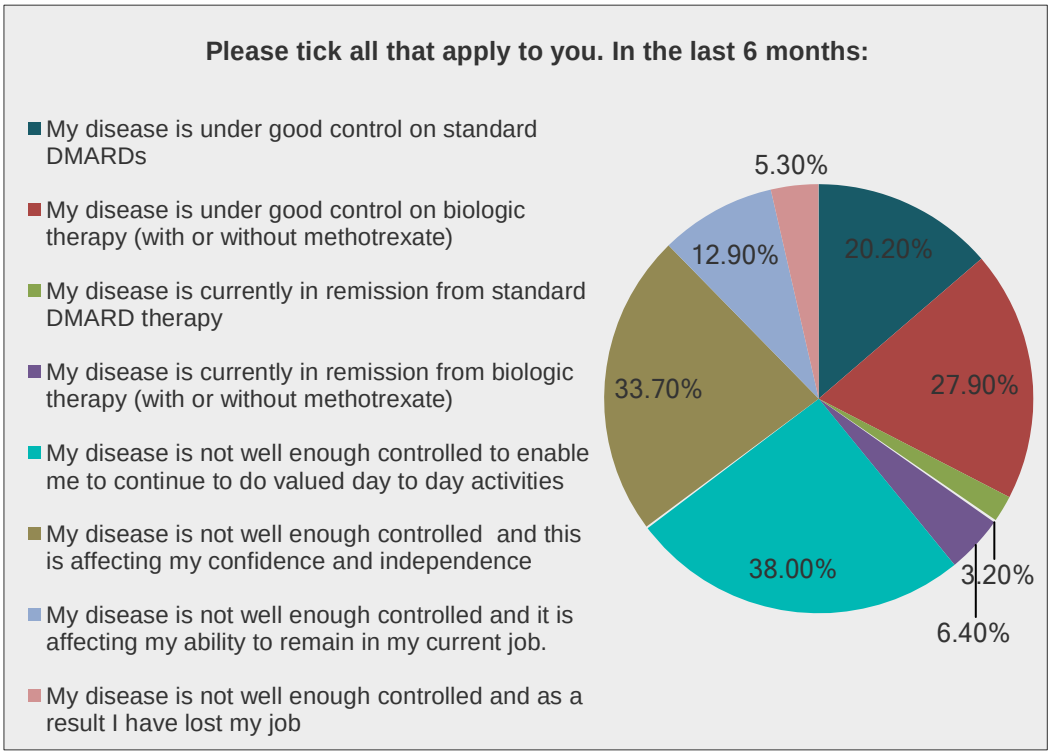
On a scale of 1-10 (where 1 is not severe at all and 10 is very severe), how has your fatigue been in the last 6 months?

Answer Options	1	2	3	4	5	6	7	8	9	10	Rating Average	Response Count
	18	37	51	56	77	87	##	186	135	80	6.75	848
											answered question	848
											skipped question	9



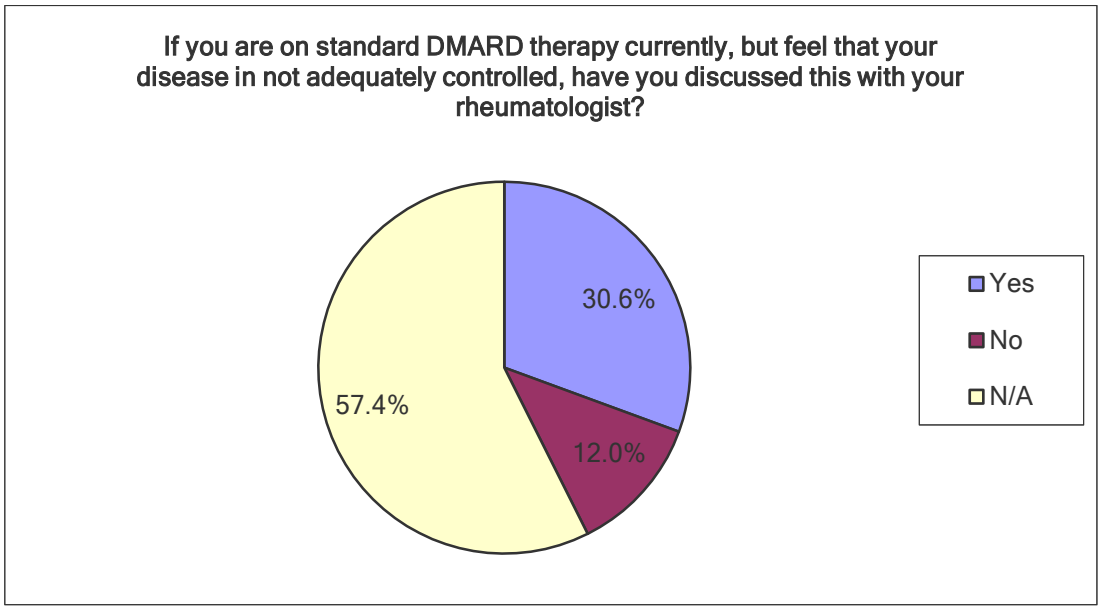
NICE review of RA drugs

Please tick all that apply to you. In the last 6 months:		
Answer Options	**Response Percent**	**Count**
My disease is under good control on standard DMARDs	20.2%	170
My disease is under good control on biologic therapy (with or without	27.9%	235
My disease is currently in remission from standard DMARD therapy	3.2%	27
My disease is currently in remission from biologic therapy (with or without	6.4%	54
My disease is not well enough controlled to enable me to continue to do valued day to day activities	38.0%	320
My disease is not well enough controlled and this is affecting my confidence and independence	33.7%	284
My disease is not well enough controlled and it is affecting my ability to remain in my current job.	12.9%	109
My disease is not well enough controlled and as a result I have lost my job	5.3%	45
	answered question	**843**
	skipped question	**14**



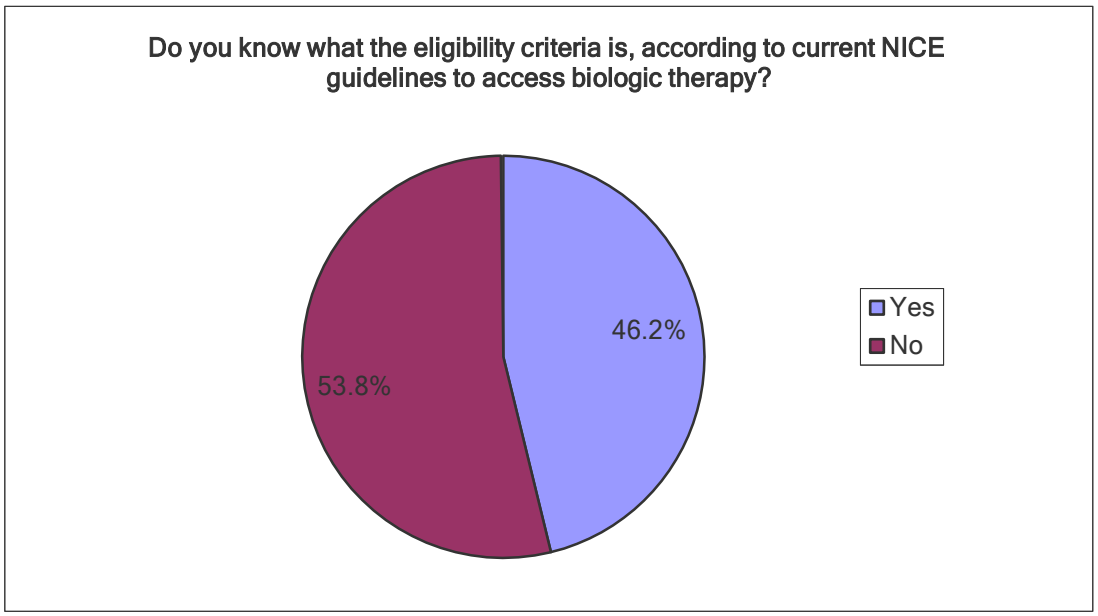
NICE review of RA drugs

If you are on standard DMARD therapy currently, but feel that your disease in not adequately controlled, have you discussed this with your rheumatologist?		
Answer Options	**Response Percent**	**Response Count**
Yes	30.6%	245
No	12.0%	96
N/A	57.4%	460
	answered question	801
	skipped question	56



NICE review of RA drugs

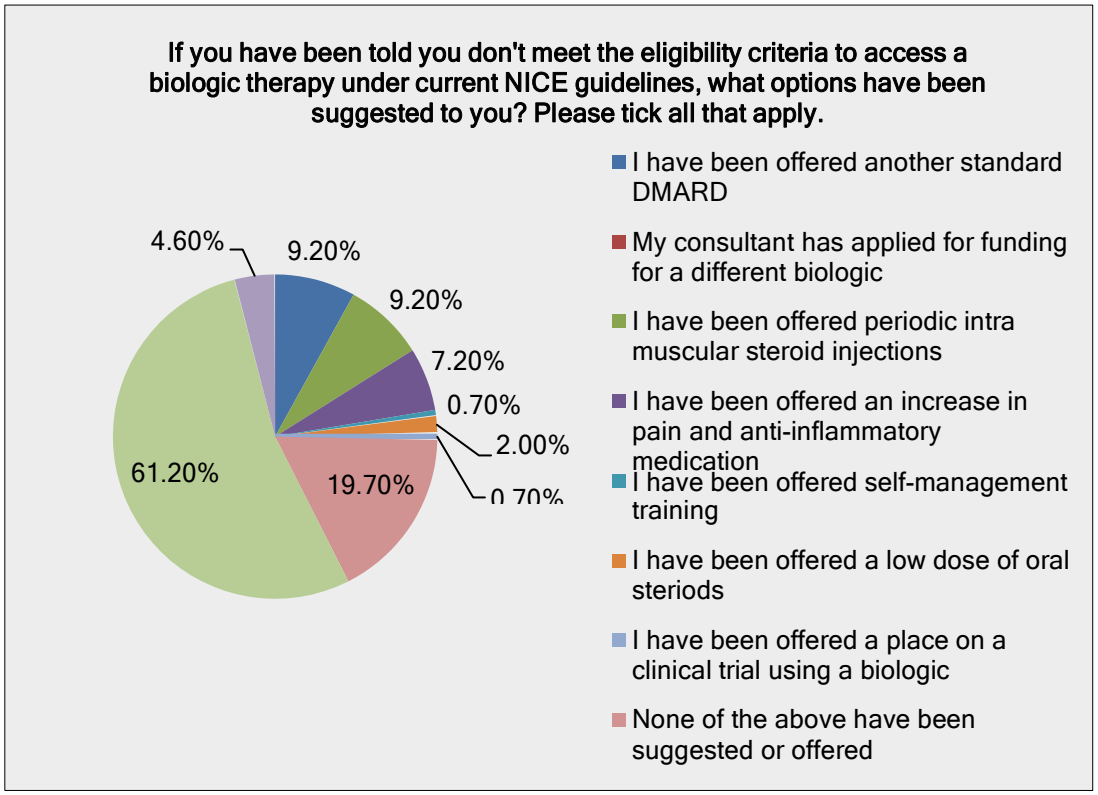
Do you know what the eligibility criteria is, according to current NICE guidelines to access biologic therapy?		
Answer Options	Response Percent	Response Count
Yes	46.2%	390
No	53.8%	454
	answered question	844
	skipped question	13



NICE review of RA drugs

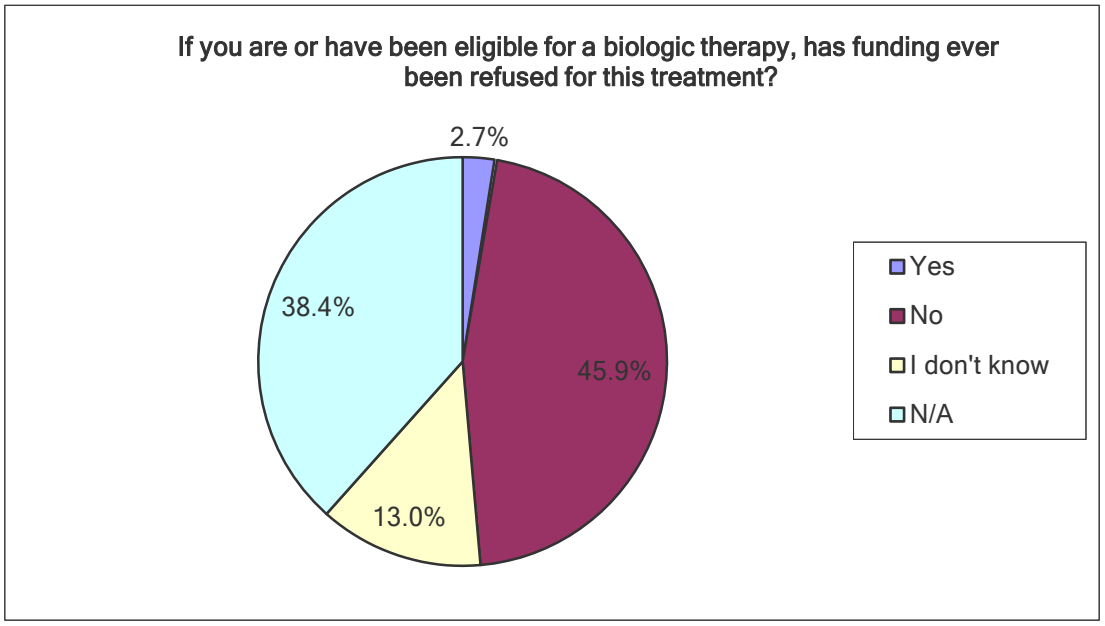
If you have been told you don't meet the eligibility criteria to access a biologic therapy under current NICE guidelines, what options have been suggested to you? Please tick all that apply.

Answer Options	Response Percent	Response Count
I have been offered another standard DMARD	6.1%	48
My consultant has applied for funding for a different biologic	1.5%	12
I have been offered periodic intra muscular steroid injections	8.7%	68
I have been offered an increase in pain and anti-inflammatory medication	6.1%	48
I have been offered self-management training	1.7%	13
I have been offered a low dose of oral steriods	5.0%	39
I have been offered a place on a clinical trial using a biologic	1.0%	8
None of the above have been suggested or offered	13.1%	103
N/A	68.5%	538
Other (please specify)	6.1%	48
	answered question	785
	skipped question	72



NICE review of RA drugs

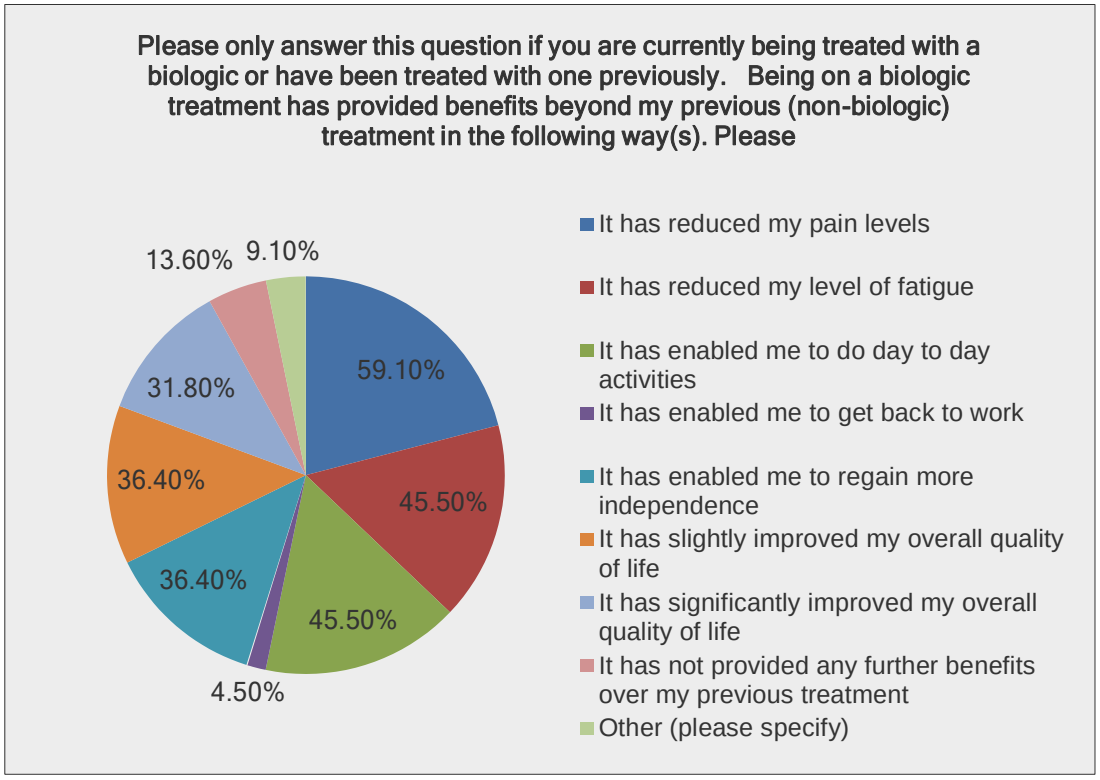
If you are or have been eligible for a biologic therapy, has funding ever been refused for this treatment?		
Answer Options	Response Percent	Response Count
Yes	2.7%	22
No	45.9%	377
I don't know	13.0%	107
N/A	38.4%	315
	answered question	821
	skipped question	36



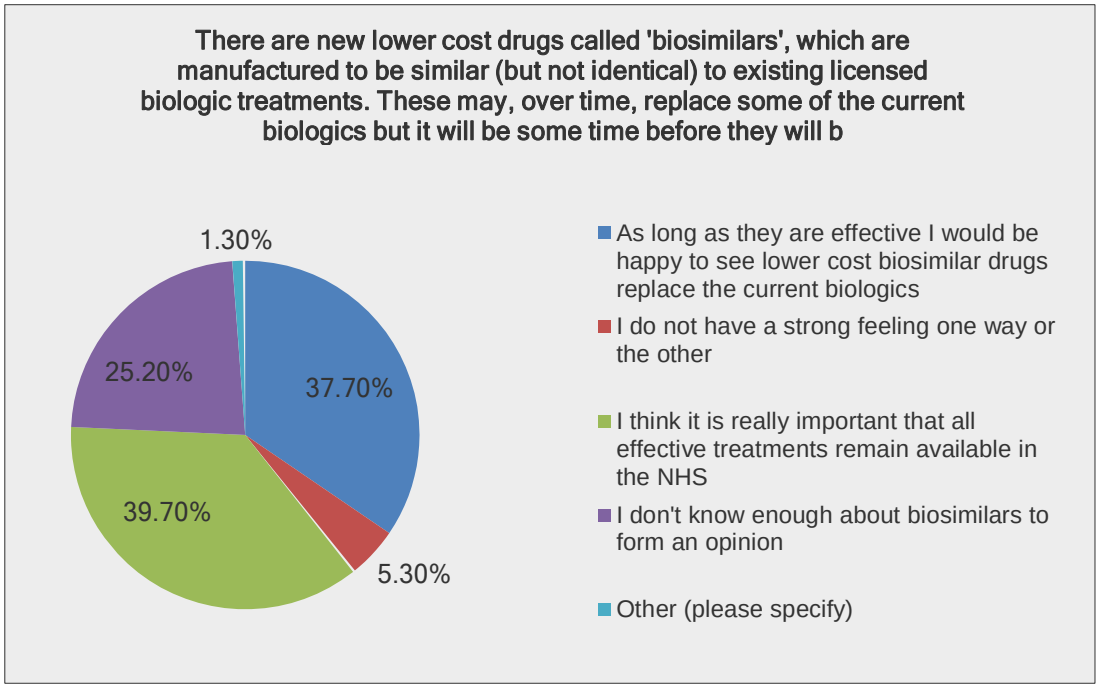
NICE review of RA drugs

Please only answer this question if you are currently being treated with a biologic or have been treated with one previously. Being on a biologic treatment has provided benefits beyond my previous (non-biologic) treatment in the following way(s). Please tick all that apply.

Answer Options	Response Percent	Response Count
It has reduced my pain levels	75.7%	367
It has reduced my level of fatigue	54.0%	262
It has enabled me to do day to day activities	64.9%	315
It has enabled me to get back to work	18.6%	90
It has enabled me to regain more independence	48.7%	236
It has slightly improved my overall quality of life	26.6%	129
It has significantly improved my overall quality of life	56.1%	272
It has not provided any further benefits over my previous treatment	7.4%	36
Other (please specify)	14.4%	70
	answered question	**485**
	skipped question	**372**



NICE review of RA drugs

There are new lower cost drugs called 'biosimilars', which are manufactured to be similar (but not identical) to existing licensed biologic treatments. These may, over time, replace some of the current biologics but it will be some time before they will be widely used in the NHS. Which of the following statements best reflects your view on this? Please tick one.

Answer Options	Response Percent	Response Count
As long as they are effective I would be happy to see lower cost biosimilar drugs replace the current biologics	33.8%	282
I do not have a strong feeling one way or the other	4.3%	36
I think it is really important that all effective treatments remain available in the NHS	46.3%	386
I don't know enough about biosimilars to form an opinion	29.1%	243
Other (please specify)	3.8%	32
	answered question	834
	skipped question	23