Review of NICE guidelines for anti TNF therapy

SurveyMonkey

1. We want to start with a few questions about you. Do you have a diagnosis of ankylosing spondylitis and / or axial spondyloarthritis?

	Response Percent	Response Count
Yes	**99.5%**	**605**
No	0.5%	3
	answered question	**608**
	skipped question	**0**

2. Do you live in?

	Response Percent	Response Count
England	**94.8%**	**567**
Northern Ireland	0.3%	2
Scotland	2.5%	15
Wales	1.5%	9
Other	0.8%	5
	answered question	**598**
	skipped question	**10**

3. Are you...?

	Response Percent	Response Count
Male	**61.2%**	**341**
Female	38.8%	216
	answered question	**557**
	skipped question	**51**

4. How old are you?

	Response Percent	Response Count
Under 18	0.0%	0
18-24	2.5%	14
25-34	10.1%	57
35-44	22.6%	127
45-54	22.6%	127
55-64	**23.0%**	**129**
65+	19.2%	108
	answered question	**562**
	skipped question	**46**

5. How long ago were you diagnosed with ankylosing spondylitis / axial spondyloarthritis?

	Response Percent	Response Count
Less than 1 year	9.0%	51
1 to less than 5 years	23.0%	130
5 to less than 10 years	13.8%	78
10 to less than 15 years	8.0%	45
15 to less than 20 years	10.4%	59
20 + years	**35.9%**	**203**
	answered question	**566**
	skipped question	**42**

6. Now thinking about medications, which, if any, of the following medications are you currently taking for your AS / axial spondyloarthritis?

	Response Percent	Response Count
Not on any medications	5.1%	29
Simple pain relief such as aspirin or paracetamol	23.2%	132
Anti inflammatories (NSAIDs) such as diclofenac, ibuprofen, naproxen, Celebrex or Arcoxia	**55.8%**	**317**
Co-codamol	20.2%	115
Opioids such as morphine patches or tramadol	18.7%	106
Steroid tablets / prednisolone tablets	3.2%	18
Steroid injections	6.9%	39
Methotrexate	7.0%	40
Sulphasalazine	8.8%	50
adalimumab (Humira)	27.3%	155
certolizumab pegol (Cimzia)	0.0%	0
etanercept (Enbrel)	15.3%	87
golimumab (Simponi)	3.9%	22
infliximab (Remicade)	2.1%	12
Other medications	14.6%	83
	answered question	**568**
	skipped question	**40**

7. What difference, if any, has your anti TNF therapy made to your life?

	Response Count
	272
answered question	272
skipped question	336

8. What do you see as the benefits of anti TNF therapy for you?

	Response Count
	269
answered question	269
skipped question	339

9. And what do you see as the downsides of taking anti TNF for you

	Response Count
	271
answered question	271
skipped question	337

10. Now we want to get your views on some of the issues that will be discussed in this review of current NICE anti TNF guidelines. There are currently five anti TNF drugs licensed by the European Medicines Agency for the treatment of ankylosing spondylitis. However, only three of these have so far been approved by NICE. The three approved by NICE for ankylosing spondylitis are: Adalimumab (Humira) Etanercept (Enbrel) Golimumab (Simponi) Another anti-TNF drug, Infliximab (Remicade) was not approved by NICE for ankylosing spondylitis in 2008 on the grounds of cost, although it is available for people with conditions like rheumatoid arthritis. The main difference between infliximab and the other available anti TNF therapies is that it is administered in an outpatients clinic by an infusion (drip) every 8 weeks. Do you think NICE should make infliximab available to people with ankylosing spondylitis?

	Response Percent	Response Count
Yes	**90.8%**	**453**
No	9.2%	46
	answered question	**499**
	skipped question	**109**

11. What do you see as being the potential advantages or benefits of infliximab over the other anti TNF therapies?

	Response Count
	397
answered question	**397**
skipped question	**211**

12. What disadvantages, if any, can you see with making infliximab available?

	Response Count
	357
answered question	**357**
skipped question	**251**

13. Are there any groups of people with AS who you think would particularly benefit from access to infliximab?

	Response Count
	336
answered question	**336**
skipped question	**272**

14. Certolizumab pegol (Cimzia) was launched onto the market earlier this year. It is administered every 2 weeks by a pre-filled syringe. It has been approved by the SMC (Scottish Medicines Consortium) for use in Scotland but is currently only approved by NICE for rheumatoid arthritis. Do you think NICE should make certolizumab pegol available to people with ankylosing spondylitis?

	Response Percent	Response Count
Yes	**90.9%**	**440**
No	9.1%	44
answered question		**484**
skipped question		**124**

15. Why do you say this?

	Response Count
	433
answered question	**433**
skipped question	**175**

16. Both adalimumab (Humira) and certolizumab pegol (Cimzia) are licensed to treat axial spondyloarthritis as well as ankylosing spondylitis. Non radiographic axial spondyloarthritis is where x-ray changes are not present but you have symptoms. Around 7 in 10 in this group have visible inflammation which shows on an MRI. 3 in 10 may not have any change visible on the MRI despite symptoms of back pain and other symptoms of inflammatory disease including: • Episodes of uveitis ((inflammation in the eyes) • Crohn's disease or ulcerative colitis (inflammatory bowel disease) • Psoriasis • Inflammation in the heel of the foot • Inflammation in the fingers or toes • Elevated markers of inflammation in blood tests • HLA-B27+ Scotland and Wales have approved adalimumab (Humira) and certolizumab pegol (Cimzia) for the treatment of people who have non-radiographic axial spondyloarthritis. Do you think NICE should make adalimumab and certolizumab pegol available for this group of people?

	Response Percent	Response Count
Yes	**92.9%**	**419**
No	7.1%	32
answered question		**451**
skipped question		**157**

17. What do you think would be the advantages or benefits of doing this?

	Response Count
	339
answered question	**339**
skipped question	**269**

18. What disadvantages, if any, can you see with doing this?

	Response Count
	281
answered question	**281**
skipped question	**327**

19. Are there any groups of people who you think would particularly benefit?

	Response Count
	260
answered question	**260**
skipped question	**348**

20. Under current NICE guidance, people with ankylosing spondylitis can only try one anti TNF. If this is not effective, or if the effectiveness decreases or wears off over time there is nothing in NICE guidance to allow for a change in therapy. Do you think NICE guidance should change so that if the first anti TNF does not help with symptoms within the first 12 weeks, people can try a second anti TNF?

		Response Percent	Response Count
Yes		**97.6%**	**438**
No		2.4%	11
		answered question	**449**
		skipped question	**159**

21. How do you think this change might help or benefit people with AS?

	Response Count
	389
answered question	**389**
skipped question	**219**

22. Do you think NICE guidance should change so that if the effectiveness of one anti TNF therapy wears off over time, a second can be tried?

	Response Percent	Response Count
Yes	**97.8%**	**436**
No	2.2%	10
	answered question	**446**
	skipped question	**162**

23. How do you think this might help or benefit people with AS?

	Response Count
	351
answered question	**351**
skipped question	**257**

24. Do you have any personal experiences that you would like to share that might be relevant to any of the issues in this survey?

	Response Count
	294
answered question	**294**
skipped question	**314**

25. Do you have any other comments on these issues?

	Response Count
	228
answered question	**228**
skipped question	**380**