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Dear Dr Longson,

Appraisal consultation document for adalimumab, etanercept and infliximab for rheumatoid arthritis

We welcome the opportunity to respond to NICE's preliminary recommendations on the sequential use of TNF-α inhibitors in the treatment of rheumatoid arthritis.

Rheumatoid arthritis is a debilitating long-term condition, which can have a profound impact on the lives of those who have the condition. Successful treatment with TNF-α inhibitors has been positively life-changing for many people with rheumatoid arthritis.

We are disappointed that following the successful appeal in 2007 and re-consideration of the topic, NICE has not recommended the sequential use of these therapies.

This recommendation comes immediately after the NICE decision not to recommend abatacept for rheumatoid arthritis. Arthritis Care is concerned that people with rheumatoid arthritis in England and Wales are step by step having their choices limited and will be missing out on therapies which could have a profound positive effect on their quality and length of life.

In concert with clinical evidence suggesting the efficacy of sequential use, (as detailed in the Arthritis and Musculoskeletal Alliance submission supported by Arthritis Care) people currently using TNF-α inhibitors feel very strongly that they must be given the opportunity to switch from one therapy to another if the first fails to work for them. One user in her thirties is frightened that one day her current therapy may cease to work. She says:

"I recently had an operation which required me to take 9 weeks off from my anti-TNF therapy. As a result I experienced a severe flare up. As well as experiencing constant pain I had no concentration and my energy levels were low. My work was badly affected.

This made me realise what life could be like if I were denied an effective treatment. I have a very aggressive type of rheumatoid arthritis and getting the right drugs is very important or I find it hard to have a "normal" life. I want to work, I want to pay my way, don't want to be stuck at home or taking up hospital beds. This decision is very short-sighted.

Since taking anti-TNF therapies, there has been no further deterioration in my condition for the first time ever. Without the correct medication I would end up costing more in benefits and NHS resources for the rest of my life.

Once you know that life can be better, it's a scary prospect that it could have been you who was denied this treatment, had the option of that life taken away. The more people know about this decision, the angrier they will be. How can people be in better health and then denied it? Don't deny people the right to live their life when the means are right in front of them."

Furthermore, this decision is in conflict with the precedent set in other EU nations, where sequential use is already available. When making a decision that goes against the grain of policy in Europe there must be extremely compelling evidence which we believe is not apparent in this case. To disallow switching to alternative TNF-α inhibitors when it is allowed elsewhere is unjust and will lead to England and Wales being the "poor man" of Europe, indeed of the UK itself.

A person with arthritis in Northern Ireland or Scotland may still have access to further TNF-α inhibitors, creating stark inequalities across the UK. The following quote is from a man who has had access to three TNF-α inhibitors over the past 5 years, in Northern Ireland;

"I have had rheumatoid arthritis for 27 years, I was diagnosed aged 12.
I had been through many different kinds of medication- anti-inflammatories, gold injections and methotrexate. After receiving my first anti-TNF therapy in 2001, my life completely changed. I didn't need anti-inflammatory medication any more, I was active and able to live my life to the full.

Unfortunately, in spring 2006 I unexpectedly developed an allergic reaction to the therapy and it gradually stopped working. I experienced a heavy and frightening relapse. Unable to get out of bed, I relied on my son to care for me where before I had been independent. I ended up being hospitalised for several weeks, given morphine for the pain.

I switched to a different anti-TNF therapy. This pulled me out of the worst of it. It managed the condition, but I still felt fatigued and required anti-inflammatories.

After several months it was decided that this was not working as well as it could, and I switched to a third anti-TNF. This brought me back completely, I got my old energy back. In fact, I feel stronger now than I was on my first therapy.

I never understood what it must be like to be diagnosed with arthritis late in life, to lose the mobility you once had. Now I know. When my anti-TNF therapy failed, I was agitated, depressed, house-bound and reliant on other people. I have a new appreciation for life now.

You cannot and should not put a price on someone's quality of life. These drugs mean the difference between a full life and one of dependence, pain and depression for me. The decision not to allow switching to alternative anti-TNF therapies is frightening".

A TNF-α inhibitors user from Scotland adds;

"I had an allergic reaction to infliximab and was put on etanercept. I was shocked by how bad my condition got when I could no longer take infliximab. I spoke to my rheumatologist and he told me that without the option of using etancercept he doesn't know what we could have done. Thankfully it worked.

Preventing someone from accessing alternative anti-TNF therapies is ruining their quality of life. I don't necessarily mean in terms of jobs, employment, I mean down to the little day to day things you just can't do. NICE must listen to patients".

Although we acknowledge that there will remain the possibility of sequential use in cases of adverse reaction, these examples clearly illustrate the need for this to be an option for all people with severe RA.

Rheumatoid arthritis is a debilitating condition which if not managed effectively can lead to a high burden on NHS resources in lifelong care. It would appear that the prior recommendation and relative cost-effectiveness of rituximab has distorted the market, making cost-effectiveness greatly outweigh clinical effectiveness in all subsequent considerations of TNF-α inhibitors. This short-sighted view fails to take into account that long term costs in ongoing care, including surgery, and palliative care which accompany ineffectively managed rheumatoid arthritis, in many cases will outweigh the short-term cost of switching to alternative TNF-α inhibitors.

Through this decision, the appraisal committee is asking people with rheumatoid arthritis to accept a future of pain, disability and eventually palliative care, rather than effective treatment. The positive changes to quality of life afforded by TNF-α inhibitors are profound and should not be easily dismissed.

Decisions of such impact as this must be made only with compelling evidence which examines more than the cost-effectiveness of the treatment. We consider that the balance of cost-effectiveness to quality of life needs more careful consideration, and urge NICE to reconsider its decision.

Yours sincerely,

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