Comments on the ACD Received from the Public Through the NICE Website

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a patient it is currently a lottery whether the anti-TNF you try first will be the one that helps you. In my experience there is a very different response to different anti-TNF?s and to Rituximab and there is no way to know which will be successful in advance. NICE?s decision to limit the opportunity to try more than one anti-TNF In point 4.1.makes treatment a lucky dip. Clearly there is a problem about research to justify costs of trying different anti-TNF?s. Surely the information already exists in every consultant?s case files. Why is it not possible to collect and analyse this existing information and to offer alternative anti-TNF?s to patients while instituting proper, uniform data collection. This would mean patients in category 1.4. would not have to suffer for another three years while waiting for Â someone to institute the research NICE wants.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/23/2010 9:09:00 PM

Name	[redacted]
Role	NHS Professional
Other role	Consultant Rheumatologist
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	Patients with severe RA have very significant morbidity, disability, poor quality of life and increased mortality. Â This

recommendations)	disease is so bad we should allow them more than one chance to improve their disease control. If NICE recommendations are followed these patients with the most severe disease will be left without any form of treatment once they have failed one anti-TNF therapy and Rituximab. This is unethical when there are available treatemts that have been proven to work. Rituximab should be available as an alternative to anti-TNF therapies in patients who have failed conventional DMARDs (without the requirement of failing an anti-TNF therapy first. The response to Rituximab is of a similar order to anti-TNF therapies, the mode of and frequency of delivery suits certain patients better than self injections or 8 weekly infusions and it is cheaper.
Section 2 (clinical need and practice)	A DAS 44 would be a better scoring system to use as the DAS 28 discriminates against patients who mainly have lower limb disease (i.e. foot, ankle and knee involvement)
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	The REFLEX trial should not have been excluded from review - why was a placebo controlled trial excluded?
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	NICE appear to have moved the goal posts when assessing the use of Tocilizumab in RA (in comparison to their reviews of anti-TNF therapies). Â The efficacy is virtually identical to that of anti-TNF therapies, the cost is the same, SEM have approved it so why have NICE refused it? Â For those with the very worst RA not responsive to anti-TNF therapy it is a very good additional possible treatment and should be available. Â I have seen people with extremely severe RA who are unable to work and have carers because of the severity of their disease and who have failed anti-TNF therapies go into remission and go back to work having been treated with Tocilizumab. These must be individuals where interleukin 6 is driving their disease rather than TNF.
Section 8 (proposed date of review of guidance)	
Date	3/23/2010 5:25:00 PM

Name	[redacted]
Role	Patient
Other role	Athritis Care self help group / campaigns
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a patient I was not allowed to upgrade to Rituximab without first trialing methotrexate which I then suffered side affects. The Llefnomide which was introduced at the same time as

	methotrexate was not taken into consideration which I have been taking since the clinical trials were processed
Section 2 (clinical need and practice)	Need more atention to the cause of flare-ups which can be brought on by pressure, physical or mental. More information to the patient to cope with arthritis involving pain and exercise
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	Prevention is always better than cure and is also more cost effective. Suspected R.A. should be nipped in the bud at the earliest signs without a postcode lottery . This could save millions
Section 5 (implementation)	More information should be given to the general public in laymans terms which can be passed via voluntary groups or workshops
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	As above but not everyone is pc literate
Section 8 (proposed date of review of guidance)	Autumn 2010
Date	3/23/2010 2:36:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe there is sufficient evidence to support the use of a second anti-TNF agent where one has failed. I have a number of patients with severe RA that have responded to one agent and not to another. These patients have Â severe disease and should be given the maximum opportunity to try available treatments. There is still a lot we dont know about disease sub-groups within RA that respond differently to different agents - it may be that in the future we are able to target treatments based on the patients pharmacogenetic profile. But until then we need to try the different agents to find one that works for an individual patient.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for	

further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/23/2010 9:56:00 AM

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	We conducted an audit and found that 50% of patients had stopped their first anti-TNF within 6 months. Â This demonstrates an important need for considering options after failure of one anti-TNF. We have demonstrated that different anti-TNF agents work through different mechanisms and therefore it seems logical to at least try one other ant-TNF after failure of first anti-TNF. Â For patients who are rheumatoid factor this guidance means that there are no therapeutic options after failure of anti-TNF since rituximab is not generally effective in patients who are rheumatoid factor negative.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/22/2010 10:01:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	This document would be much more useful if it included guidelines for newer drugs also: tocilixumab and certiluzumab

recommendations)	(perhaps also golimumab) are or will be competing for this same market. What status will they have if not included?
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/22/2010 1:10:00 PM

Name	[redacted]
Role	Patient
Other role	member of Dorset ARMA local network
Location	England
Conflict	no
Notes	I have had RA since 1979 onset at age 13. I am extremely concerned at the limitations this guidence will cause in the treatment available to manage this awful disease. I urge NICE to reconsider this devastating decison and ask that a more favourable guidence can be drawn up. I cannot understand that out of the 7 currently licensed & available biologic therapies, I and other RA patients will be allowed only one chance at a TNF. Â I read that possibly two chances may be available if I/we can go onto a research programme. However I also undertand that the biologics register is closed to new patients so rules out this chance and the likelihood of finding myself in an area with a research programme in reality rules out any chance of being offered a 2nd anti TNF treatment. So in effect if my one treatment fails my only chance of a therapy that may help is then Rituximab. I will have no opportunity to try any of the other available therapies that NICE will not approve. This is not and cannot be acceptable. I/We need access to more therapies such as Tocilizumab and abatacept. Please can you consider when deciding on these guidelines that RA is not one disease but involves different sub-groups. Mine is RF+ and is an aggressive progressive disease. I and other RA patients react differently to different therapies, and when going onto anti TNF therapy I/we cannot know, at this time, which therapy will work for us.

	By denying the opportunity to try the available treatments I and others like me are potentially destined to return to the use of DMARDs/steroids that have failed us. Why are RA pateints to be treated differently then crohns patients? I understand that Â 2 TNFs + maintenance dose are allowed and it is left to clinical judgement? Why is it acceptable to limit us to one try of Anti TNF but acceptable to allow another group of patients with auto immune disease the chance of a 2nd? Why are our clinicians not allowed the same freedom to exercise clinical judgement in the use of TNF therapy? I have had 30 years of living with RA, the pain, the joint damage, the gradual erosion and loss of the ability to function and perform normal everday tasks and the numerous and painful joint operations. The growing expense of buying equipment, moving into suitable accommodation, having to buy automatic cars, loss of income etc. Believe me,I know all about the cost of RA. To see these new therapies and treatments being developed, but seeing them Â denied to RA patients is devasting. Therefore again, I urge you to reconsider this latest guidence decision. many thanks [redacted] (please contact me with your response on the advised email address.) The following is the ACD in respect of drugs for treatment after failure of a TNF inhibitor: appraisal consultation document and closes for comments on 24th March, 2010 - click on link below to make any comments http://www.nice.org.uk/guidance/index.jsp?actionarticle&o47716

	The following is the ACD in respect of guidance on the use of Tocilizumab and closes for comments on 25th March, 2010 ??? click on the link below to make any comments http://www.nice.org.uk/guidance/index.jsp?actionarticle&o47661 Thank you very much for your support. [redacted] [redacted] NRAS [redacted], Rheumatology Futures Group Project PLEASE NOTE MY NEW EMAIL ADDRESS: [redacted] then Rituximab. This really is not acceptable. We need access to more agents with different modes of access such as Tocilizumab and abatacept and the fact that NICE still does not get that RA is not one disease but involves different sub-groups which mean that patients react differently to different therapies, is dispiriting in the extreme. We have canvassed all of our members, volunteers and friends and asked them all to go to the NICE website (links below) and register their views and we urge you to do the same. If you could also forward this email to any local colleagues to ask them to do the same, that would be very much appreciated. We believe that a large volume of clinicians going onto their website arguing for more access to biologic therapies may have an impact. Our reason for believing that this method may have an effect is based on the example in Crohns disease - NICE recommended only 1 TNF, many clinicians logged on and made their views felt. The decision was subsequently over-turned and 2 TNFs + maintenance dose were allowed and it was left to

	clinical judgement. Whilst I don???t think we have a cat in hell???s chance of choice of therapy being left to ???clinical judgement??? in RA, citing your views may help get us further than where we are right now. Thank you for your help. See relevant links and by when dates below: The following is the ACD in respect of drugs for treatment after failure of a TNF inhibitor: appraisal consultation document and closes for comments on 24th March, 2010 - click on link below to make any comments http://www.nice.org.uk/guidance/index.jsp?actionarticle&o47716 The following is the ACD in respect of guidance on the use of Tocilizumab and closes for comments on 25th March, 2010 ??? click on the link below to make any comments http://www.nice.org.uk/guidance/index.jsp?actionarticle&o47661 Thank you very much for your support. [redacted] [redacted] NRAS [redacted], Rheumatology Futures Group Project PLEASE NOTE MY NEW EMAIL ADDRESS: [redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	I have had RA since 1979 onset at age 13. I am extremely concerned at the limitations this guidence will cause in the

preliminary recommendations)	treatment available to manage this awful disease. I urge NICE to reconsider this devastating decison and ask that a more favourable guidence can be drawn up. I cannot understand that out of the 7 currently licensed & available biologic therapies, I and other RA patients will be allowed only one chance at a TNF. Â I read that possibly two chances may be available if I/we can go onto a research programme. However I also undertand that the biologics register is closed to new patients so rules out this chance and the likelihood of finding myself in an area with a research programme in reality rules out any chance of being offered a 2nd anti TNF treatment. So in effect if my one treatment fails my only chance of a therapy that may help is then Rituximab. I will have no opportunity to try any of the other available therapies that NICE will not approve. This is not and cannot be acceptable. I/We need access to more therapies such as Tocilizumab and abatacept. Please can you consider when deciding on these guidelines that RA is not one disease but involves different sub-groups. Mine is RF+ and is an aggressive progressive disease. I and other RA patients react differently to different therapies, and when going onto anti TNF therapy I/we cannot know, at this time, which therapy will work for us. By denying the opportunity to try the available treatments I and others like me are potentially destined to return to the use of DMARDs/steroids that have failed us. Why are RA pateints to be treated differently then crohns patients? I understand that Â 2 TNFs + maintenance dose are allowed and it is left to clinical judgement? Why is it acceptable to limit us to one try of Anti TNF but acceptable to allow another group of patients with auto immune disease the chance of a 2nd? Why are our clinicians not allowed the same freedom to exercise clinical judgement in the use of TNF therapy? I have had 30 years of living with RA, the pain, the joint damage, the gradual erosion and loss of the ability to function and perform normal everday tasks and the numerous and painful joint operations. The growing expense of buying equipment, moving into suitable accommodation, having to buy automatic cars, loss of income etc. Believe me,I know all about the cost of RA. To see these new therapies and treatments being developed, but seeing them Â denied to RA patients is devasting. Therefore again, I urge you to reconsider this latest guidence decision. many thanks

	[redacted]
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/21/2010 10:49:00 PM

Name	[redacted]
Role	NHS Professional
Other role	Hon Sec of British Society for Rheumatology
Location	England
Conflict	no
Notes	I am dismayed to understand that our patients with RA once they have failed one Anti-TNF will not be allowed to try another except in the context of a drug trial. I was involved in the recentNICE review of Certolizumab which I think got a fair hearing. We presented all the data on why additional drugs was needed then. Thus it is discouraging that you now appear to be saying that patients will not be able to use them.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	I am dismayed to understand that our patients with RA once they have failed one Anti-TNF will not be allowed to try another except in the context of a drug trial. I was involved in the recentNICE review of Certolizumab which I think got a fair hearing. We presented all the data on why additional drugs was needed then. Thus it is discouraging that you now appear to be saying that patients will not be able to use them.
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	

Section 8 (proposed date of review of guidance)	
Date	3/18/2010 3:50:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Even though Rituximab is effective following anti TNF therapy for those patients who are RA Sero-negative this drug will be less effective. Therefore Abatacept provides a further treatment option for that group of RA patients.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/18/2010 1:16:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My personal experience as that I first received Humira, which had no noticable effect on my RA. After several months I was given Enteracept (allowed in Scotland) which immediately gave me almost 100% relief allowing me to continue working full-time. It seems incomprehensible that a second anti-TNF is not allowed in England after the failur of a first.
Section 2 (clinical need and practice)	This seems OK except that the DAS score does not take into account knees and feet.
Section 3 (The technologies)	No comment
Section 4	There does not seem to be enough evidence to justify denying

(Evidence and interpretation)	a 2nd anti-TNF to patients following failure of a first. My own case and anecdotal evidence from other patients in Scotland who have been prescribed 2 sequentially favours the use of a 2nd. It h
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	More randomised trials essential. Use scotland where many people have had sequential anti-TNFs
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/18/2010 10:42:00 AM

Name	[redacted]
Role	NHS Professional
Other role	Past President, British Society for Rheumatology
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is disappointing that the original decision to prevent switch therapy has been maintained in the face of significant clinical evidence that patients may benefit it is in my view a decision underpinned by a failure to understand that the various preparations used either act in different ways on TNF, or act at a different point in the inflammatory pathway (abatacept - and tocilizumab). To consider them all as identical because of their end effect is equivalent to suggesting that a patient whose blood pressure is not controlled on a beta-blocker becomes ineligible for treatment with a calcium channel antagonist. Whatever the assessed health costs it is also clear that England is now not only out of step with Europe, but in relation to tocilizumab is out of step with Scotland. The preconditions for use are more stringent in England than in most of the rest of the EU. Â This raises the question of equity of access and might be deemed an unacceptable infringement of human rights in the European Court. I have made some detailed comments below but am unable to complete these because of a character entry limit.
Section 2 (clinical need and practice)	No comments
Section 3 (The technologies)	There is oversimplification of the exact mode of action of the TNF blockers. Â They are not identical. Â Two work by binding to TNF the other appears to work by acting as a false substrate and binding direct to receptors (it may also have some action in T
Section 4 (Evidence and interpretation)	Para 4.3.4. Â While it is true that accelerated use od standard DMARDs may hasten the time to a biologic there is some

	evidence that early DMARD use, particularly in high doses or in combination, is more effective and may thus reduce the need to progress
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	It should also be noted that some patients have severe allergic reactions to rituximab and are thus denied any further treatment should this occur. Clinicians find it very difficult to manage resistant patients who know that there are other possible treat
Section 7 (related NICE guidance)	I have noted my concern about tocilizumab which has been approved in Scotland this produces an internal UK inconsistency which Â takes us back to postcode prescribing.
Section 8 (proposed date of review of guidance)	
Date	3/16/2010 1:45:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/15/2010 10:01:00 AM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	As a sufferer from RA I have tried numerous Dmards with no lasting success and moved to etanercept in 2003 and am currently doing well. However these proposed guidelines would Â severely limit future alternative treatments should I either develop any side effects or its efficacy diminish. I have observed that no two peoples experience of RA or response to the different drugs are the same Â and feel that we need more alternatives and not less. I only moved on to an anti TNF drug when all dmards had been tried and either not been efficient or had had serious side effects - a return to these would not be an option and steroids have too many side effects. I am unable to imagine how it would feel to be Â struggling with uncontrolled RA again whilst knowing that there are actually were treatments out there but not being able to access them.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/12/2010 2:42:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	page crashed - did my comments get through?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for	

further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/11/2010 10:49:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Wales
Conflict	no
Notes	I am involved in clinical trials of biologic agents in RA - no personal payment received for this.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Not recommending abatacept or switching of anti-TNF agents effectively limits RA patients to 2 biologic agents during their lifetime, which may be a particular problem for those patients who are RF/antiCCP negative and may therefore not respond as well to rituximab.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	The differences in duration of the infusions also impacts on units and staff. Specifically, the shorter abatacept infusions allow for more patients to be treated than the longer rituximab infusions, despite the requirement for more frequent infusions with
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/11/2010 10:06:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	

Section 2 (clinical need and practice)	
Section 3 (The technologies)	I think cost alone should not influence decisions esp. as ACR responses are good.What is important to me as Â aclinician is to have available a wide choice of biologics to use in patients who have severe RA and have failed on anti TNF alpha.
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/11/2010 3:28:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	Perhaps I have missed it, but I cannot see that the cost-effectiveness calculations take into account the lack of spending on the anti-tnf that is no longer being taken. In other words, the cost of eg rituximab should be calculated as the differential bet
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	The research should surely take some account of the likely prognosis of the patients and the severity of their RA. There is large variation in the severity of the illness in individuals and in its progression. Some patients are likely to become severely i
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/9/2010 11:35:00 PM

Name	[redacted]
Role	Patient
Other role	Retired RGN
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I suffer from severe RA & have been taking anta TNF since 2004. Â I am horrified & very frightened to learn of the possible outcome of NICEs decision regarding swapping from one anti TNF to another, as I am living proof that this does work. Â I commenced on Etanercept in 2004 which slowly became less effective in controlling my disease & subsequentally changed to Adalimumab in 2007 which I am currently taking. Â Should this happen again then where would I be, as there would be no futher option other than one treatment option which may not be a suitble for me. Â I could & would not be able to go back to that time when I required constant care & supervision & had no quality of life. Â The amount of pain was unbearable & indescribable. Â It is unacceptable & I feel criminal that there are proven therapies which are not being made accesible to patients like myself. Â I would like the decision makers to have to suffer the amount of pain for just one day, & im sure their minds would be changed.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/9/2010 5:16:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	it is devastating news to me that should my TNF inhibitor Humira become less effectiove in the treatment of my RA, I would not be allowed to change drugs to another TNF inhibitor. Before using Humira (Adalimumab) I was unable to move

	easily.... not able to wlk, so use of my muscles was limited..... now i am able to do virtually anything. It is truely wonderful, and I want the option to be able to switch to another TNF inhibitor should Humiras effect become ineffective.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	I work and pay a lot of tax. I would not be able to do this if I did not use Humira (Adalimumab). I lead a normal fulfilled life and contribute to society.
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/7/2010 8:30:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why is the supply of these drugs undertaken by commercial companies? Â Surely NHS supply would lessen th cost.
Section 2 (clinical need and practice)	The patient suffers far more than set out in 2.4. Â There is no assessment of the physological damage of the diease taken into account.
Section 3 (The technologies)	The cost of not allowing the drugs is far more from increased costs of ineffectively treating the disease - causing more visits to GPs, Â use of ancillary services such as Podiatry, occupational health. Â This is without the loss of tax and NI and increas
Section 4 (Evidence and interpretation)	Why are patients taking these drugs at present not being followed up and their results being used as part of the study? Â Obviously more money need to be put into studying the effect of drugs on this disease.
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	See above re follow up of patients. Look at the dreadful cost to patients. Â Two years ago I had a successful business and lived a full life. Â Now I have lost my business and just exist in a pain filled exhausted stupor.
Section 7	

(related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/7/2010 3:59:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I just cant understand Nices stance on the restrictions being placed on the use of Biologicals for the treatment of Rheumatoid Arthritis, from which Ive suffered since 1996. Because TNF and other biologicals were not available in 1996 (in Sheffield) I subsequently lost both of my ankle joints (left is fused with 3 metal pins, right is a total replacement) and had to retire early (aged 55) in 2004 from a high paying job in IT (Â£63k pa in 2004) to live on a pension of Â£11k + DLA. Having had all of the usual suspects as treatment initially (DMARDs like Sulphasalazine, Steroids and Methotrexate) plus many other pills I eventually got onto Entercept injections - these worked great for about 18 months and then stopped working. Subsequently I got onto a trial drug (2H7 - a MAB derivative) which has given me back my life. The trial has been running over 2 years and has been extended to 5 and is looking a definite to market drug. Once the trial is complete then under your new guidelines I will NOT be entitled to this new treatment as I have failed already on Enbrel and my health will then dive back to how it was pre-trial with numerous other joints eventually needing replacement, possible total infirmity and possible death causing a huge increase in cost and strain on precious NHS resources - I fail to understand the rationale behind your decisions if you believe it to be a cost saver then you must have very inferior project managers, statisticians and decision makers to have made this cost saving decision.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	

Section 8 (proposed date of review of guidance)	
Date	3/7/2010 12:15:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/6/2010 5:31:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I would just like to say that I am very disappointed with the decision that NICE has made with regard to approval of alternative TNF inhibitors Â I have suffered with RA for the past 26 years and have tried almost every DEMARD that has been on the market, all of which made little or no improvement to my condition. I was also on high doses of steroids for almost 10 of those years, consequently leaving me with a low bone density, for which I take Ibandronic Acid. Four years ago I was offered Etanercept as a last ditch attempt to improve my condition. Â Within four weeks I was a different woman, leading an almost normal life. If this medication ceased to be effective for me what hope do I have? This type of action by NICE no doubt, reduces research funding as it gives the public the perception that if they donate to

	research for new drugs, the new drugs will not be authorised onto the market by NICE and therefore, what is the point !
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
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Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/6/2010 4:07:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Rituximab should be available to those who respond inadequately to DMARDS without any requirement to have tried a TNF inhibitor first. Â The sequential use of different TNF inhibitors should be available for use at any time and not only for research purposes. Patients may respond successfully to a different anti-TNF after having an unsatisfactory outcome using a previous drug. We also need the maximum possible options left open to us.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	

Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/6/2010 3:23:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	How many of these people who make these judgements actually have Rheumatoid Arthritis. If they had got it the outcome would be very different as they would do anything to releieve the pain and suffering it causes. I have paid my taxes for over 40 years so
Date	3/6/2010 12:28:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	yes
Notes	As a patient with moderately active RA I am currently taking Etanercept and leading a relatively normal life. However if this fails and I am not allowed to try another of the biologic drugs then I would have to give up my job and become housebound, possibly need a carer and be a burden on society. Â How can one part of the UK be able to have these drugs and not others. Â Nice need to look at the wider picture!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	I feel that if a TNF inhibitor does not work for a patient then

preliminary recommendations)	others should be allowed without reference to research. Â Keeping people mobile and as fit as possible for as long as possible not only enhances their lives but stops them becoming a burden on the NHS regarding all the extra help and medication both for physical and mental problems that they will require.
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/5/2010 7:30:00 PM

Name	[redacted]
Role	Patient
Other role	retired
Location	Scotland
Conflict	no
Notes	how dare you deprive thousands of RA sufferers of Biological Medicine when it works so well. I am sure your decision is purely financial SHAME ON YOU from [redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	SHAME ON YOU NICE this is so obviously a financial decision/
Section 2 (clinical need and practice)	I would be unable to walk without Humira and there were far to many restrictions Before I was given biologics with the result that some of my points were damaged beyond repair.....SHAME ON YOU
Section 3 (The technologies)	The freedom from pain is worth the risk of some infections.....ITS ALL ABOUT MONEY isn,t it Â SHAME ON YOU
Section 4 (Evidence and interpretation)	Money Money Money Â shame on you
Section 5 (implementation)	You shouls insist on results from ALL hospitals, there seem to be many uncontrolled results.....get a grip and do your job properly, you are playing with peoples lives.....ESPECIALLY MINE
Section 6 (proposed recommendations for further research)	make all biologics report experiences to a central body.....impartial..... no drug companie invloved, only rheumatolagists and people with RA.

Section 7 (related NICE guidance)	Your guidance is crap get into the real world and talk to doctors nurses and patients about Anti-TNF,s
Section 8 (proposed date of review of guidance)	Yuo must do better SHAME ON YOU
Date	3/5/2010 6:29:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	I have been injecting with HUMIRA since 2005 with 100% improvement after failing on other drugs,It has really given me my life back. I don,t want to see these antiTNF drugs withdrawn
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/5/2010 5:51:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I have been on humira for 2years now and it has transformed my life. I first started on embrel but did nothing for me, so was lucky enough to be changed. There is no doubt in my mind that I would have ended up with depression and in a wheel chair, costing the nhs far more money. Now I am able to be an active member in society, and help others.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	

Section 2 (clinical need and practice)	
Section 3 (The technologies)	
Section 4 (Evidence and interpretation)	
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Section 8 (proposed date of review of guidance)	
Date	3/5/2010 5:27:00 PM