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

Name	[redacted]
Role	Patient
Other role	MEDICAL PRACTITIONER (RETIRED)
Location	England
Conflict	no
Notes	I RETIRED FROM STRONGLY EVIDENCE BASED GENERAL PRACTICE IN 2004 DUE TO MYELOMA
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	NICE should perform its primary duty in advising best practice based on best evidence in an independent , transparent & EXPEDIENT manner.
Section 2 (the technology)	The pharmaceutical industry needs NHS cost moderation but NICE should not weaken its independence by being Government`s cost control tool. Transparency would be preserved by declaring separate consultations on cost issues after clinical excellence recomendation reports.
Section 3 (manufacturer's submission)	Cost analysis could also include prolongation of patient`s income tax payments & spending activity , both of which have positive fiscal effects re the cost of increased longevity , if cost is so important. Pharmaceutical companies should develop a symbiotic relationship with the NHS as each needs such a partnership. EVIDENCE BASED CARE SHOULD NOT BE COMPROMISED IN THIS PROCESS.
Section 4 (consideration of the evidence)	The evidence strongly supports this reccomendation and it should be implemented without further delay.
Section 5 (implementation)	Delay in availability of strongly evidence based interventions erodes the position of an allegedly independent arbiter of clinical excellence to one of a cost control arm of central government.
Section 6 (proposed recommendations for further research)	I have enjoyed 13 months treatment free remission after 3 cycles of Bortezomib. Prior to this I enjoyed 54 months treatment free after high dose melphalan/autologous stem cell transplant. Vast series of one but I contend that paying tax , spending my disposable income and being a constructive member of society

	for this time Â has been a worthwhile outcome for the NHS investment in the management of my condition.
Section 7 (related NICE guidance)	No comment.
Date	17/02/2009

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (the technology)	
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	In clinical practice, THalidomide is widely used. there is now a licensed preparation. At the moment, clinicians are requesting funding on exceptional grounds as thalidomide causes peripheral neuropathy. Where in this guidance will PCTs be able to clarify when Thalidomide should be used first as it is more cost effective for the NHS if the generic (unlicensed) preparation continues to be used. This guidance appears to discount Thalidomide as its unlicensed (which it isnt any more). Is there any evidence of effectiveness and harms vs Thalidomide?
Section 5 (implementation)	
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	
Date	16/02/2009

Name	[redacted]

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I was diagnosed with Monoclonal Gammopathy of Unknown Significance (MGUS) in 2002. I progressed and was diagnosed with Smoldering Multiple Myeloma in 2008 at the age of 42.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Brilliant news but why is it only recommended after two therapies, is this because this is when the drug is most effective or is this to cut costs a little.
Section 2 (the technology)	The drug seems to have a lot of side affects, are the side affects manageable/treatable in most cases? Why on earth does it cost this amount of money to produce these drugs, are they technically difficult to manufacture or does the ingredients/chemicals cause the cost to be so high?
Section 3 (manufacturer's submission)	This is far too technical for me to understand but what I did understand was the possibility of extending life for myeloma patients for approx 3 years. This has to be good news because in those three years more treatments will evolve and further life extensions may be possible.
Section 4 (consideration of the evidence)	I am pleased at the way the committee has fully analyzed the data and weighed up the evidence. I am even more pleased that the decision to make the drug available on the NHS has been reached. Thank you also to Celgene for funding treatment beyond two years.
Section 5 (implementation)	Please consider the effects of a 3 month wait for this treatment to become available. Please consider issuing the drug for patients who need it now.
Section 6 (proposed recommendations for further research)	
Section 7 (related NICE guidance)	The review date for technological guidance seems fair, although a partial review in January 2009 may prove useful.
Date	04/02/2009

Name	[redacted]
Role	Patient
Other role	Haematology Patient Representative
Location	England

Conflict	no
Notes	I have 16 years experience in Multiple Myeloma, diagnosed in 1993. I have had every suitable treatment including 2 transplants, Thalidomide, Bortezomib and Lenalidomide. I have no bone pain and minimal side effects, being more capable than most 70 year olds.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Initially restrict use of Bortezomib and Lenalidomide to treatments of last resort as judged by doctors, ie no other suitable treatment. Insist on recording treatment in full, following trial procedures. Use the experts (eg Royal Marsden) to determine data needs, and collate all UK data for immediate use by doctors, and by NICE at review stage. Allow selected specialist doctors more flexibility in choice of patients, to improve knowledge at all stages of the disease. Consider patients like me taking a new trial, then Lenalidomide on relapse to regain fitness (Lenalidomide gives me almost instant full remission), before repeating the process, hence turning Myeloma into a manageable disease.
Section 2 (the technology)	Too few patients have been treated to be sure about side effects and long term effects. Post code lottery has denied many doctors access to these drugs. There is a learning curve, and this should be acknowledged in costings. The patient is not the only one to gain from spending £4368 per cycle. Try to discourage doctors from using Lenalidomide to simply stabilise disease, ie encourage them to look for suitable new drugs and trials to give remission rather than stability.
Section 3 (manufacturer's submission)	You do Myeloma patients a dis-service by forcing manufacturers into your preset format, comparing one drug with another, and deciding which is best. For Myeloma patients older treatments generally can only be used once. When the patient is lucky they may give good remission with minimal side effects. Any additional new drug or treatment is of potential benefit, even if only giving 3 months remission.

	Do not lump all results together in an average! The cost should be broken down into "Full remission" (worth the expenditure) Fails to prevent progression (dont waste money once position is clear) Partial remission (normally stop when results show treatment has been ineffective, but maybe allow some stabilising treatment). You quote figures like £43,000 and more. I got full remission on 3 cycles (<£13,500).
Section 4 (consideration of the evidence)	Put a Haematologist on your committee. Dont worry about the sequence -thats for the specialists to consider on a patient by patient basis. Concentrate on adding new drugs/treatments to the armoury. Let them become routine only when fully studied (eg 3-4 years). It is said there is a new treatment arriving every year. Excellent - each one becomes the one of last resort,and subject to NHS testing by all the specialist doctors. One day the specialists will decide to drop the older chemo treatments. It is next to useless worrying about whether Bortezomib is better than Lenalidomide. It all depends on how it works for each individual patient. Dont trust the statistics, there are too few patients, and too much variability. Each patient is almost unique. We just want the chance to achieve that next remission! I have done 16 years with every drug going, and I want another 20 years to put me in my working 90s!
Section 5 (implementation)	Minimise costs by using each new drug as drug of last resort. If no patient is left stranded, or told to "go away and die" as a commissioner told me, then there will be no screaming patients and families in the media. Thats where I am today. I want a boost with Lenalidomide. My appeal to the public is due in the Oxford Mail tomorrow. I shall probably remain in this position until 3 months after you publish your final decision. I am "all right Jack". I am fit enough to join some manufacturers trial. Others are not, and its my job to help them, so please help me to help them.
Section 6 (proposed recommendations for further research)	Bortezomib should be treated just like Lenalidomide. To patients they both have the same result, provided they work. We need both, each being a fallback drug in case the other does not work.
Section 7 (related NICE guidance)	Please make it possible for NHS doctors to collect and collate

	the information for you to make valid decisions. These decisions should be independent of manufacturers trials, which are designed for showing drugs are safe at the limits, and to help with their marketing.
Date	30/01/2009