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)	1.1 I do not support this recommendation. Â To deny patients access to this drug on cost alone whilst acknowledging its clinical effectiveness is indefensible and flies in the face of human decency. Â This is the second time that NICE has rejected a novel drug for Myeloma patients on cost grounds only to be forced to partially overturn that decision. We are people not faceless objects and deserve better - we didnt choose to have a rarer cancer that costs more to treat so why do you appear to punish us for it in putting cost over life? This drug does not just offer a few weeks of extra life but months and years. Â I know because I have had it and am still here - alive, well and living a near-normal life. Â Do not deny that to other patients - this decision must be overturned. 1.2 Yes		
Section 2 (the technology)	2.2 Not all the decribed side-effects will affect every patient ie I did not experience neutropenia, thrombocytopenia, anaemia or rash.		
Section 3 (manufacturer's submission)	As the clinical effectiveness of Revlimid has been acknowledged I do not offer any comments on this section.		
Section 4 (consideration of the evidence)	4.3 Bortezomib is restricted by NICE to treat first relapse patients only. I have had both drugs on studies with Dexamethasone (a drug with appalling side-effects). Â Lenalidomide is far better tolerated, is taken orally and requires minimum clinical and hospital time (cost-effective). Â It is proven (and as I experienced) to be effective with low-dose dexamethasone which makes patients quality of life so much better during treatment. 4.13 I am 63, have had myeloma for 5 years, been treated with both Bortezomib and Lenalidomide. Â I have had a working holiday in Kenya and shortly going to New Zealand - thanks to these drugs. Â You have the opportunity to negotiate cost with the drug companies to reduce pricing - please take it. Â In a civilised country we should not be having this debate. Â Despite top-ups most people will not be able to afford them - please dont leave us to die prematurely because of cost when this drug has been proven to work.		
Section 5 (implementation)	No comment		
Section 6 (related NICE guidance)	No comment		
Section 7 (proposed date of review of guidance)	This date is unacceptable - we need the drug now not in 3 years time. Â How many will die unnecessarily in the meantime? Â Further, NICE has accepted the need to consider severity in its appraisals and this must be implemented now not in 2011. Â NICE has been charged by Alan Johnson to speed up appraisals and use an appraisal format that allows more flexibility in the consideration of rare cancers. Â This is a golden opportunity to put right a dreadful wrong - nothing less than an overturn of this decision will be acceptable to the myeloma community. Â Please act to reverse this decision.		

Name	[redacted]

Role	other		
Other role	Daughter of a multiple myeloma patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	1.1 This is a terrible decision for people who have multiple myeloma and is effectively a death sentence for people who have relapsed myeloma. Current first line oral treatments (eg CTD) can prolong life and give a good quality of life after treatment for a certain length of time but when a relapse occurs effective oral treatments like Revlimid should be available on the NHS as this has been shown in trials to give patients remission of a few months to several years. Although Velcade is available, this is a much more difficult treatment to administer (the patient has to be hospitalised)and the drug often has more powerful side effects than Revlimid)- and so if Revlimid is offered to patients this would save a lot of money on hospital admissions -and this important factor should be taken into consideration.		
Section 2 (the technology)	The cost seems high but what is this when compared to many billions which the government have recently utilised to bail out banks and financial institutions? The decision not to give Revlimid on cost grounds is immoral, unfair and unjustified in my opinion. Would the manufacturer have any scope to reduce the price if they knew that the drug would be used for myeloma patients throughout the NHS? This should be clarified before a final decision is made.		
Section 3 (manufacturer's submission)	I think doctors should be allowed to use their clinical judgement in prescribing Revlimid to those who they think would benefit most. Clinical trial data can only be taken at face value - and it seems clear that there was a statistically significant increase in life span in trials of people who took Revlimid. It is not morally acceptable in my opinion to cite lack of cost effectiveness as a reason for not prescribing the drug - this goes against the principles of the NHS.		
Section 4 (consideration of the evidence)	I would be interested to know if any members of "The Committee" have/had any close relatives who have experienced this horrible disease? Â How easy it must be for people in ivory towers to look at the "evidence" on paper and to make decisions such as 4.13 above. As a close relative of a myeloma patient I find this decision abhorrent and offensive- in particular to hard-working British citizens (born in this country) who have the disease and who have paid tax and National Insurance for all their working lives - only to find that they lose out in the "Lottery" of illnesses which the NHS will provide effective treatment for. This is appalling and unfair. The committee should take this factor in consideration when looking at who should be able to have this treatment. Regarding lack of NHS resources - perhaps the government need to re-appraise their priorities.		
Section 5 (implementation)	NO comment		
Section 6 (related NICE guidance)	NO comment		
Section 7 (proposed date of review of guidance)	7.2 This date will be too late for many people who already have multiple myeloma and who would benefit from Revlimid,and should be reviewed again in 2009.		

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)	1.1 this is fine provided the previous therapy was ineffectual 1.2agreed
Section 2 (the technology)	2.1 agreed 2.2 there are always some side effects 2.3
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	Although Revlimid is licenced and appears to be an effective treatment it seems to have been rejected by NICE because of cost. There is no doubt that the cost is very high, but the numbers of recipients is low so the overall cost to the service is probably reasonable and the effect on the few sufferers receiving treatment (and their carers) profound. Ease of administration of the tablets also frees up NHS time and reduces costs. I would hope that NICE would reconsider its position based on realistic numbers of treatments provided since it would generally not be feasible for "top ups" to be afforded by sufferers families. Yours sincerely, [redacted]		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Although Revlimid is licenced and appears to be an effective treatment it seems to have been rejected by NICE because of cost. There is no doubt that the cost is very high, but the numbers of recipients is low so the overall cost to the service is probably reasonable and the effect on the few sufferers receiving treatment (and their carers) profound. Â I would hope that NICE would reconsider its position based on realistic numbers of treatments provided since it would generally not be feasible for "top ups" to be afforded by sufferers families.		
Section 2 (the technology)	Ease of administration of the tablets also frees up NHS time and reduces costs.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			

Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes	no		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	as before		
Section 2 (the technology)	as before		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	other		
Other role	family member of sufferer		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	As ther are clear indications it would benefit this small group of patients who until very recently had little or no hope of an extended life one prior therapy should not preclude them from the benefit of Lenalidomide and the hope of months if not years of remission		
Section 2 (the technology)	Indications are that the benefit outweighs many of the adverse effects. No way could this group of patients be able to afford this drug privately unlike for example the Alzeimer drug.Funding this expensive drug would only be for a small group of people for whom the outlook is grave		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review			

of guidance)	

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)	Disagree with committees recommendations, as follows Lenalidomide is a useful anti-myeloma drug particularly in combination with dexamethasone and in combination with alkylating agents.(BJHaem 137 268-269 2007 Morgan et al) Clinicians require flexibility to use these drugs to treat drug resistant patients and thereby prolong patients lifespan. Some patients have severe neuropathy with thalidomide therapy and can be effectively treated with lenalidomide without exacerbation of their neuropathy. The cost analysis by the committee assumes the manufacturers recommended dose will be used throughout - may patients experience some haematological toxicity which results in lower doses being used, thereby reducing costs substantially.		
Section 2 (the technology)	25% of patients in RCD study by Morgan et al BJHaem 137 268-269 had a dose reduction of lenalidomide. A dose of 15 mg results in a substantial cost reduction.		
Section 3 (manufacturer's submission)	The cost analysis assumes patients stay on full dose, in reality 25% of patients undergo dose reduction mitigating costs substantially. Duration of therapy is also often reduced.		
Section 4 (consideration of the evidence)	The committees evidence review is already out of date. There are many publications in the literature of combination therapy which are superior to bortezomib and dexamethasone, with 90-95% response rates, whilst these studies still have to produce long term data, it is inappropriate to restrict clinicians practice to evidence from 2-3 years ago, as opposed to 2008 data.Restricting the order in which lines of treatment are given eg the use of bortezomib at first relapse, to comply with NICE actually increases the costs of therapy, when clinicians might have preferred to repeat first line therapy where they had already seen a satisfactory initial response and good duration of response. Bortezomib could then have been used later in therapy. The NICE process is therefore flawed, in distorting clinical practice from UK Haematologists who would otherwise have exercised prescribing patterns, based on clinical experience, and tailored to the individual patient.		
Section 5 (implementation)	see above		
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)	Re- reviewing this subject in 2011 is inappropriate given the rapid pace of change in myeloma research. New data is already available on combination therapy of alkylating agent, bortezomib and dexamethasone which has not been considered by NICE at all.		

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

Section 1 (Appraisal Committee's preliminary recommendations)	Drug companies must be encouraged to reduce the price of a new clinically effective drug. Why should critically ill patients not have access to a drug available in Europe? N.I.C.E. must reconsider its draft it approves of higher cost treatments, therefore why not Revlimid?
Section 2 (the technology)	The balance of effectiveness and side-effects is good for this drug. Self-medication at home is possible thus reducing NHS workload. Â Furthermore this is another treatment option where others may not be succeeding, and it would not be fair for critically ill patients to carry such an enormous financial and psychological burden.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Enormous sums have been invested in Revlimid and it has been found to be an effective drug. It should be used for the benefit of patients who would otherwise die. The problem of cost must be resolved by negotiation with suppliers and by increased efficiency within the NHS. It is cruel and unacceptable for patients to be denied a drug which they know exists and which they know could save their lives. It is inconceivable that the nation could deliberately condemn patients to death when there is a proven treatment available. If Revlimid is not prescribed and brought into general use for affected patients, advances in the treatment of Myeloma and, possibly other related diseases, will be put at risk. Revlimid should be included in reforms that NICE is proposing in its recently announced consultation on approving higher cost treatments for rarer diseases.		
Section 2 (the technology)	Revlimid is known to be effective with mimimal side effects - making it a drug upon which patients can remain in the longer term. Revlimid can be self-medicated obviating the need for hospital visits and thus saving stress, strain and expense for the patient and saving money for the NHS. Revlimid is beneficial for all Myeloma patients helping them not only to live longer but to survive long enough to benefit from future advances in the treatment of Myeloma. Revlimid can improve overall survival and can help to allow patients to lead an increasingly independent life. The cost of Revlimid to individual patients is virtually out of reach for all but a few but, as the disease is relatively rare, the overall cost to the nation via the NHS is not unmanageable - particularly, if the NHS worked on increased savings through efficiency at all points -		

	especially within day-to-day administrative systems.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	friend of myeloma sufferer		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	For patients to know that there is a licensed product that is clinically effective but they cannot have access to it is a cross that may prove too much to bear.		
Section 2 (the technology)	NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Patient		
Other role	Police control room operator		
Location	England	**Conflict**	no
Notes	I have suffered with MM for 12 years but the last 12 months have been far the worse as I have Â had to fight for my treatment Â as well as my life.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	For patients to know there is a licensed, clincally effective treatment out there but cannot have it is a cross they should not have to bear		
Section 2 (the technology)	NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refactory to other therapies and will help them live longer to benefit from future developments		
Section 3 (manufacturer's submission)			

Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	For section 1 Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid For section 2 Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden. However, where the		

	treatment in question costs thousands of pounds every month, such as Revlimid, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	For section 1 Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month - far too much for Myeloma patients to pay themselves.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	For section 1 Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid For section 2 Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden. However, where the treatment in question costs thousands of pounds every month, such as Revlimid, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable		
Section 2 (the technology)			
Section 3 (manufacturer's submission)			
Section 4 (consideration of the			

evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	daughter in law		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	he should have this drug when he needs it		
Section 2 (the technology)	he has been paying into the NHS for years and should get the drug when he needs it		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

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)	I am a myeloma patient currently in remission. I fully understand that the time will come, within months or 1 - 2 years, when I shall need more treatment. Evidence from your own studies shows that Rivlimid is the most likely to prolong my life to an acceptable quality for the longest time. Having paid full taxes in a 40 year working life, I find it unacceptable that your recommendation will preclude me from the best treatment. If cost is the issue then please explore with the supplier ways of dealing with the problem. You did it with Velcade - why not with Rivlimid?		
Section 2 (the technology)	Rivlimid is convenient to take and has less side effects than other treatments. It has been shown to be effective even when other treatments cannot be tolerated.It is in routine use in USA and most European countries. Under this guidance the use of Rivlimid in England will be minimal - effectively limited to wealthy patients who can afford it. By opening it up to wider use, Nice should be able substantially to reduce cost per patient.		

Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	Under this guidance the use of Rivlimid will be minimal - effectively limited to wealthy patients who can afford it. By opening it up to wider use, Nice should be able substantially to reduce cost per patient.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I am a patient who has had a stem cell transplant following initial chemotherapy. I relapsed and was treated very successfully with Velcade as part of the myeloma 9 trial. Velcade was initially deemed poor value in the treatment of myeloma by NICE. Although I am currently in good health I know that myeloma will return. I feel that Lenalidomide Â should be available to consultants for use as they feel appropriate.		
Section 2 (the technology)	Myeloma is a very individual disease and patients response to various treatments is very indiviual. Until Lenalidomide has been been trialed on a patient it is impossible to judge if it is a appropriate treatment for that patient.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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)	I am very disappointed at this. This medication should be made available to all patients for whom their doctor believes it is the best treatment for them.		
Section 2 (the technology)	Irrespective of cost I believe that this medication should be available when required. I have a friend who has received all the other treatments and all have failed to date - He is now on Revlimid and at		

	present this is working. While this medication will not suit everyone and others are avilable which are less costly I believe that patients should always get the best treatment for them irrespective of cost. If more funds are required then taxation should be increased if nescessary
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	Everything comes down to cost - while I understand funds are not infinite pressure should be brought to bear on politicians to increase funding - if nescessary taxation could be increased or savings made elsewhere -there is always plenty of money for arms and to pay for our politicians and other less important things than the health of all
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	i assume the recommendations are based solely on financial grounds. Otherwise it would be perverse to exclude a chemical that has just received the Prix Galien award and about which the IMF has said that it along with other novel therapies signals an era where incurable cancers will be transformed into chronic manageable diseases and where other developed countries provide their citizens with it e.g the Dutch following the HOVON MM working groups recommendations for lenalidomide to be used from a range of other chemicals the choice being on an individual basis. I support NICEs position only if it is a tactic to put pressure on the manufacturer to reduce its prices.		
Section 2 (the technology)	It seems to me that the chemical offers clear benefits in certain cases and should be available for use in such.		
Section 3 (manufacturer's submission)	As a layman it is difficult to make any comment on this except to note that there are so many variables that comparisons must be somewhat tentative.		
Section 4 (consideration of the evidence)	I hope that NICE feels in principle that the chemical should be available on the NHS. I appreciate that money is not unlimited and priorities must be set. Myeloma is a very unfortunate accident which happens to very few of us and is not knowingly caused by any lifestyle abuse such as alcohol,drugs,smoking,obesity etc. This is a factor which should play a role in deciding financial priorities. As with all accidents I believe the NHS should do whatever it can to save and prolong life. The money needs to be found by negotiating with the manufacturer (why not on an EU wide basis for more leverage) and maybe a Velcade type deal. We should have a health service to match the best on offer to our European neighbours.		
Section 5 (implementation)			
Section 6 (related NICE guidance)	As an almost certain future candidate for Bortezomid I would like to thank NICE for giving me the opportunity to take whatever advantage there may be in using the drug in terms of extending my life and its quality. I hope one day to be able to thank it for the use of		

	lenalidomide. I am a big supporter of the NHS. I trust it will not let me and other myeloma sufferers down.
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	I am an ex Health Professional and have personal knowledge of someone suffering from multiple myeloma		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that it is unethical to refuse to make Lenalidomide available to myeloma patients. It has been proven clinically effective and there is alot of data to support its use against Myeloma. If cost is the only reason then it should be a priority for this issue to be addressed so that the situation can be resolved and patients can be successfully treated. The disease causes a great deal of pain and suffering to patients and it is unfair to withhold licensed treatment that could be clinically effective. The knowledge that there is an effective treatment that they cannot have only adds to the suffering. Myeloma treatment should be a special case because it is a rare disease which causes severe symptoms which will prove fatal if no treatment is given. The rarity of the disease obviously has cost implications because research is expensive and the market for the drug may be less. Nice should make allowances for this. It is unjust that patients cannot be treated because they have a rare disease!		
Section 2 (the technology)	The cost of the treatment means that very few patients could afford to pay for the treatment out of their own pockets (topping up). Revalamid is so far the only developed treatment for Myeloma where the patients could remain on the drug long term because it is clinically effective and the side effects are relatively minor compared with other chemotherapy treatments. In addition the fact that Revlamid can be given orally makes it very convenient for both patients and hospital staff. The patient can self-medicate at home or work instead of having to visit hospital for each treatment. This must also save costs for both patient and health authorities. NHS access to Revlamid would mean that patients still have treatment options even when previous therapies are no longer working. This could help them to live long enough to benefit from future developments. Also, Revlamid is an extra therapeutic option which may be more successful than other options for many patients. It could enable many patients to get back into remission and improve their survival chances, not to mention improving the quality of life.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review			

of guidance)	

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	I have been taking Revlimid since Spring 2004 and the drug has maintained my disease in a stable condition. There was no other treatment avilable at that time so I count myself as fortunate to be included in the clinical trials for Revlimid which followed on from my being prescibed Actimid in Autummn 2003. I have been a patient at [redacted] since 2003.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I can vouch for the fact that Revlimid is indeed effective and has kept my disease under control for over 5 years, indeed I owe my life to it. The clinical trials have supported the use of Revlimid and have demonstrated the efficacy of the drug. It is unacceptable for NICE to reject it purely on the grounds of cost and to condemn many sufferers to premature death. The Government and the manufacturers should get together to discuss ways in which the costs could be reduced. Patients should not be taunted with the knowledge that there is a drug available which may extend their lives but is not to be given to them because NICE has said it is too costly. There has been no similar advance in the treatment of Myeloma for many years and other treatments such as stem cell transplant are not appropriate for many patients, including myself. I trust that the present consultation about the costs of expensive drugs for the rarer diseases will also include Revlimid (Lanolidomide). Chemotherapy is very debilitating and there is a limit to it, and patients usually cannot work, they therefore become a burden to the Governments budget, whereas on Revlimid they can continue useful lives		
Section 2 (the technology)	I have found very few side effects from Revlimid in the whole time I have been taking it. Furthermore apart from my monthly visit to [redacted] I can self medicate all other treatments require visits to hospitals with the attandant requirements for doctors and nurses to look after the patients. Any drug which allows the patient extra life also allows for the development of new treatments from which the patient can benefit. I wonder if the true costs of losing a useful member of the working community able to contribute to the overall wealth of the country has been factored into the equation when considering the costs of this drug. It seems illogical and grossly unfair to attempt to place a value on someones life expectancy, for this is what the NICE decision is doing in effect. With some cheaper drugs it would be possible for a patient to top up the cost and continue to receive the drug, but clearly Revlimid with its current high costs makes that impracticable for all but a few very wealthy patients.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			

Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	I work for a medical education company that has contracts with Millenium related to Velcade. I have never been personally involved in this work and I have no access to any information relating to this work. I am responding purely as a myeloma patient.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I do not find it acceptable to be refused access to Revlimid on cost grounds alone where NICE and Celgene have clearly failed to learn the lessons from the Velcade decision last year. It is the joint responsibility of NICE and Celgene to work out a cost structure that recognises the heterogeneity of patient response as with Velcade. This draft is little more than a pedantic argument over statistics and a public negotiotiation over Revlimid price. This has 2 clear detremental effects on patients: 1. As a 44 years old patient, my chances of achieving a good or complete response to Revlimid are not represented in this trial data. As a young patient with a rare cancer I have no hope of my likely response rates ever being truly represented by a clinical trial. I demand to be treated as an individual and my potential response to be judged by my clinicians on a personal basis. 2. Denying access to Revlimid denys me and my doctors the chance to mirror Clinical Excellence from the US. Latest data in the US show that a combination with Velcade can produce a good response at any point in disease progression or relapse.		
Section 2 (the technology)	2.1 Critically it is this difference in mode of action that makes availibility of Revlimid a critical issue as it is now being proven to have synergistic effects with Velcade and other newer agents. The clinical data available at the time of this recomendation is already out of date and does not reflect Clinical Excellence being achieved in places where access is not rationed according on cost alone. 2.3 Please set out the acceptable cost so that Celgene can consider and defend their position and so we as patients can consider if they are being reasonable in their demands.		
Section 3 (manufacturer's submission)	3.3 This data does not reflect likely survival data for this population or for me as an individual. Latest analysis suggests survival could be 5.6 years compared to 2.2 for dex alone. What is the QALY based on this data?: Multiple myeloma patients taking REVLIMIDÂ® (lenalidomide) plus dexamethasone significantly increased their survival rates.[1] A lifetime simulation yielded an estimated mean survival of 5.6 life-years with REVLIMID in combination with dexamethasone (2.2 life-years with dexamethasone alone) for patients with one prior therapy, and 4.2 life-years (1.5 life-years for dexamethasone alone) for patients with multiple prior therapies.[1] 1 Morgan,G. Overall Survival with Dexamethasone in Phase II Multiple Myeloma Trials after Adjustment for Cross-Over to Lenalidomide. Abstract 0441. EHA 14 June 2008		

Section 4 (consideration of the evidence)	4.12 This highlights the point that clinical data does not represent me or many others. We will never be represented accurately in clinical trial data due to small numbers of available patients and the older average age. I demand the right to be treated as an individual and not have my future sacrificed in statistical gamesmanship between NICE and Celgene. Can you explain where the impact of my early death on my 6 and 10 year old children is calculated in the QALY system? No one knows what a QALY will cost for me until I get the treatment. If it works pay for it. If not ask for the money back. 4.13 This ignores the potential improvement of Velcade/Revlimid combinations 4.13 Go ask the government for a banking style cancer bail out plan. Get 1% of the bank bail out budget transfered in to a cancer treatment fund. When it works Celgene get paid. When it doesnt the money goes to the NHS. Ask patients and charities to contribute a nominal fee to access the treatment if that helps. This could be also be funded by a cancer tax on the tobaco and alcohol industries.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	7.2 Many of us will be dead by 2011. There is no excuse not to review this annually, especially in light of the fact that actual clinical practice in oncology runs way ahead of formalised trials. Small-scale trials are already showing remarkable results for Velcade/Revlimid combinations at all stages of disease and relapse. You should prioritise a review of all available combination data next year. Clearly however none of this data will be available from within the UK as NICE are not allowing clinicians to use Revlimid and have restricted Velcade use to 1st relapse only. You should consider bringing in some US doctors to your appraisal committee as they will be the only doctors with the relevant direct clinical experience with these new drugs in real world application. Future analyses should also include reviews of response predictors so that rationining of drugs is based on likely clinical outcomes in targeted patients and not the blunt instrument of mean results applied to a general disease population.

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	None		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I dont think its right that a tried and tested drug which has been proven to work should be denied access on the grounds of cost alone.Why bother to have research in the first place,which in its self is costly and time consuming only to have the benefits of it laid to waste.I think it is very important that government (dept of health),NICE and the drug company that produces Revlimid get together and broker a fair price for this treatment, that is agreed by all. The Patient must not be forced to stand by and suffer when our very lives are at stake.And it must also be remembered that patients who have been told that Revlimid is their only chance of survival by their doctor only to be informed that it is not available in the area they live feel demoralised and let down.Cancer not only affects the patient but has far reaching consequences for entire families, which strengthens the		

	argument that the original judgement to deny access must be overturned.
Section 2 (the technology)	Because Revlimid is an oral treatment it has the advantage of patients not needing to make repeat hospital visits as it can be taken at home.Also the balance of effectiveness against the side-effects issue is better than previous treatments allowing Â patients to stay on the drug longer gaining better results.Revlimid will play an important part in giving patients an extended and better quality of life by making them independent and self sufficient.The government are now saying that patients will be allowed to pay for top-up treatment without losing their right to free NHS care,but this will do nothing to help Myeloma patients who dont have a sizeable bank balance or a property to sell.At Â£4368 per month Revlimid is way out of the reach of all but the most wealthy patients and this most unfair to the majority of the Myeloma community.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role	Relative of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I feel very strongly that the adverse effect of desperate frustration on a patient Â knowing that an effective treatment for their cancer exists,but that it isnt available for only financial reasons is totally unacceptable. This is with an understanding of financial constraints on the NHS but with the increasing number of cancer patients the manufactureres know that their drug will be in demand. Why are we allowing corporate greed to put patients lives at risk? Ultimately the drug company will benefit from wider use of the drug & thus the cost will reduce & their revenue increase further so ways of reducing the cost to the NHS must be considered in talks with the government, NICE and the manufacturers. I understand that NICE are now consulting on the appraisal of high cost treatments for rarer diseases which is to be welcomed but these recommendations need to apply to Revlimid.		
Section 2 (the technology)	I undertsand that the drugs effectiveness to side effects ratio is so favourable that the prognosis for increased longevity and prolonged use is good. This increases the patients chances of living long enough to benefit from new developments and discoveries. My sister-in-law has been told it would be her best chance, having been in remission only 14 months after her last treatmenton another drug. She raised over Â£3000 at her recent 50th birthday party to further myeloma research.She has modified her Â routine to accommodate treatment. Imagine what it means to her to know that she could self-medicate on Revlimid, continue to lead a very fulfilling and productive life, promote		

	education and research but no....she cant afford to as the drug is so prohibitively expensive for an individual and, though currently known to help those like her, is not available on NHS! I urge NICE to reconsider and make Revlimid available on the Â NHS to patients like my sister-in-law, who should still have such a long and fulfilling life ahead of her. I urge them to discuss with the manufacturers and the government ways of reducing the costs of the drug, perhaps in trials for its wider application.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role	member of the velcade three		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I have multiple Myeloma. I was diagnosed in 2002 when I was 39 years old. I have worked in the NHS as a nurse and midwife for 28 years, giving them the best years of my life. I have had chemotherapy (C-VAMP), stem cell transplant, thalidomide, Velcade (PAD trial) and more recently was re-challenged with Velcade. Without Velcade I may not be sitting here writing my views. However, like all drugs Velcade has its limits, therefore when the time comes I would like to have the opportunity to have Revlimid. Revlimid is a clinically effective treatment for Myeloma Sufferers. To reject this drug on cost alone is deplorable ? solutions can be found to reduce its cost, just like they were with the drug Velcade. The risk sharing scheme is one way forward. looking at issues surrounding QUALY is another way forward. I urge NICE, the Government, Consultants, and the drug manufacturer to discuss ways in which the price can be reduced, so Revlimid can be available on the NHS. it is a hard blow to patients to know that there is a licensed, clinically effective treatment out there but they can not access it		
Section 2 (the technology)	The Government has now supported co-payment allowing patients to pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month. Revlimid on the top-up system will not be affordable to many. If Revlimid remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable. Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so Myeloma Sufferers can remain on it longer term Revlimid is a more convenient treatment for Sufferers and their		

	families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work. Given orally cuts down other procedures like insertion of hickman lines that cost the NHS. Â NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role	Family Member suffers from myeloma		
Location	N Ireland	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I strongly disagree with the Appraisal Committees recommendations. The effectiveness of lenalidomide is not in dispute. It is able to achieve rapid and striking reductions in paraprotein levels. The durability of response can range from one to three years, perhaps longer. Many cancers have been cured by a combination of drugs, (childhood leukaemia, Hodgkins Disease, Lance Armstrong Disease etc), so we need to figure out how best to use the drugs we have now. The UK should be fully involved in this fight against myeloma, rather than opting out. Myeloma is not the result of an irresponsible lifestyle. Myeloma patients have done nothing to bring this illness on themselves, which is not the case with so many other illnesses currently costing the NHS (the taxpayer) countless millions. Myeloma patients deserve better.		
Section 2 (the technology)	Lenalidomide is very expensive. A price reduction with Celgene must be negotiated. In the meantime it is worth remembering that the total number of myeloma patients in the UK is between 14,000 and 20,000, and so the high cost of providing Revlimid to all those patients who need it would be relatively small in total.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)	I refer you to parag 4.4 above and the sentence "It is noted that TTP was statisically significantly increased in the len/dex arm for the whole trial population...) How can serious medical professionals involved in the delivery of high standards of treatment turn their back on that statement? Medical practitioners must be encouraged to deliver the		

	best possible outcomes for their patients and be able to test different combinations of medicines in order to be certain of the optimal sequence of agents to use. Because of the well documented side effects of medicines eg Bortezomib, doctors need to have at their disposal an effective alternative. Ruling out this option by ruling out lenalidomide is hard to justify. The Committee has completely ignored the Secretary of States pledges given to patients in December 2007 that "the NHS will work to give you access to the best possible cancer experience and outcomes" and "Your PCT will be supported in ensuring that the best possible cancer services are available to you." NICE must reconsider for the good of patients. Section 3.3 states that the time to progression was 2-3 times longer in the len/dex arm of the trial than in the dex arm. The survival rates are also better in the len/dex arm. These findings should be immediately capitalised on by the NHS instead of research being slowed down and barriers being put up. other [redacted]
Section 5 (implementation)	Performance is unsatisfactory. Government pledges ignored, patients failed, and thinking is dominated by narrow monetarist considerations to the detriment of medical excellence, leaving patients to look with envy at the life-extending treatments offered in other European countries.
Section 6 (related NICE guidance)	Interesting, but not really relevant and already out of date.
Section 7 (proposed date of review of guidance)	Do international trials not count? Do we not have one world especially in the field of medical research? Why are these decisions allowed to drag on for so long while people die?

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)	i understand from the information I have read that Revlimid is very effective and has achieved good results, so surely between yourselves, goverment and the manuafacturer you could come to some compromise with regard to the cost eg. if a patient being treated does not respond there is no charge to the NHS, or a reduced charge is made. Also if the drug is more widely available and used, by economies of scale, this will drive the cost down. Additionally, because this drug is so effective will it not reduce costs to the NHS as the patient will not have to continually attend hospital, thus allowing both Dr and Nursing staff more time in their busy working day. Patients are already stressed and knowing there is an effective treatment that is not available to them in their fight against this disease adds to the stress and isolation felt.		
Section 2 (the technology)	From the information I have read Revlimid offers the patient a treatment with less side effects than other drugs. In view of this will financial savings not be made because there will be a reduced need for other drugs to be used to combat the side effects associated with alternative drugs. Additionally there will be a reduction in the need for intensive visits to hospital, either to receive certain medications intraveneously, or to review and treat side effects being experienced		

	with other drugs. Because overtime Myeloma becomes resistant to drugs, Revlimid offers another option available to patients to extend their life.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I understand Revlimid to be a clinically effective treatment with impressive data that supports its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, I implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients. It is distressing for patients, their families and friends to know that a licensed, clinically effective treatment is out there but not acessible. Failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma. The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid.		
Section 2 (the technology)	? Revlimid is the first myeloma treatment where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term ? Oral dosing does not involve the resource and time-intensive hospital visits required for administration of intravenous treatments ? patients can self-medicate at home or at work ? NHS access to Revlimid would ensure that patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments ? Newer treatments such as Revlimid can benefit patients in		

	increasing therapeutic options available to get back into remission, improving overall survival and helping them lead an increasingly independent life ? Revlimid costs Â£4368 per month but is currently rejected by NICE. Although patients are now permitted to top up out of their own pockets the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable. Â If research has resulted in this advance then I urge you to make it available to patients.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	I understand that Revlimid is effective for myeloma with data supporting its use. To refuse it on cost is dreadful, for with some imagination costs must be able to be reduced.All parties involved must discuss ways in which the cost can be limited. For patients to know that there is a licensed and effective treatment but not available to them adds to their burden and that of the relatives at the worst possible time.		
Section 2 (the technology)	Evidently Revlimid is the first myeloma treatment to be developed where there is good balance between clinical effectiveness and side-effects allowing patients to remain on it longer term. Revlimid is a convenient treatment for patient and their family. Oral dosing avoids time-intensive visits to hospital otherwise required as patients can take it at home. Medical time and cost is also reduced. Use of Revlimid by the NHS would give patients treatment options even when other therapies are innapropriate. Although patients can now pay for treatments if the NHS does not provide them, with Revlimid costing Â£4368 per month that is an option for a negligible few.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review			

of guidance)	

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)	I was diagnosed with myeloma in April2007 which is debilitating painful and life threatening. I have been told that I shall need Revlimid a drug which is licensed and available in Europe but so far denied patients by the draft recommendation of NICE on cost effective grounds alone despite NICE accepting there is strong evidence that it is clinically effective - a cruel outcome for patients and their dedicated doctors. An urgent formula needs to be drawn up between the Government NICE and the manufacturer to make Revlimid available to NHS patients.		
Section 2 (the technology)	Myeloma patients urge NICE for a positive recommendation from this consultation. Revlimid is the first myeloma drug with excellent balance between results and side effects & substantial benefits - a break through drug taken in capsule form which needs no intravenous or hospitalisation costs. Â This should be reflected when discussing the overall cost of the drug. Revlimid and other drugs for the comparatively few patients with rare cancers should be paid for by severe cutting back of the immense bureacracy and waste in the NHS only too evident in administrative departments during my illness and demonstrated by the proffesor of oncology at Imperial College. Mike Richards recommendations must be accepted in full.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	If Goverments throughout the world took the same stance as NICE, drug companies would stop developing new treatments. Revlimid is a treatment that is proven to be effective and to reject it on cost alone is sentancing some myeloma patients to an early death.		
Section 2 (the technology)	Because Revlimid can be taken orally this must reduce the strain on already stretched NHS resources which should be off sett against the cost of the drug in QUALY terms. The introduction of Co-payment will create a two tear helth service with those who can afford receiving new treatment and those who can not - not. This can not be right and		

	the health service providing the best treatment for individual patients must be provided for everyone.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Daughter of patient		
Location	Other	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	It appears that the above recommendation under section 1.1 has been made solely on the basis of the cost of this medication. This seems totally inappropriate and is surely unaccetable given the fact that Revlimid has been shown to be a clinically effective treatment. The data to-date provides strong evidence supportings its use in myeloma and to reject it purely based on costs seems to be very narrow minded. As the daughter of a myeloma patient, to know that a licensed, clinically effective treatment is available but unobtainable, is unacceptable and inexcusable. I strongly urge NICE to reconsider its draft and to discuss with the manufacturer ways in which the price can be reduced that is acceptable to the NHS. Such discussions are surely in the best interest of the patients. As you are aware, myeloma is a rare yet severe disease with numerous challenges and it is important to allow patients access to all new and effective treatments. Please reconsider these recommendations and reconsider appraising higher cost treatments for rarer disease. Please provide these patients with the ability to access proven clinically effective treatment for this disease.		
Section 2 (the technology)	Lenalidomide (Revlimid) is the first myeloma treatment that has been developed and shown to provide a clinical effectiveness with an accetable level of tolerable side effects. This is a huge breakthrough for this patient population. The ability to provide an oral medication allows patients to self-medicate at home reducing any inconvenience of travel and any discomfort that may come with other forms of adminstration. In addition, it allows the patient to stay within the comfort of their home and easily maintain a regular lifestyle. Revlimid further provides a treatment option that extends the life of the patient providing the opportunity for the patient to benefit from any additional treatment options that may become available. This treatment will help myeloma patients lead an independent life and will improve their overall survival rate and allow them the opportunity to obtain other therapeutic options that may assist in extending their life. The current costs of the treatment make it unaffordable for the majority of patients to be able to even consider as an option. It seems unnecessarily cruel to identify a clinically effective treatment for a disease that is unobtainable.		

Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	I have had 3 friends who developed myloma. Â One is Irish and turned 70,and still alive, a close friend who developed myloma in her 40s, was in remission but not now, another friend who died unexpectedly aged 56 during treatment.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	It is very hard for people who have had previous treatment and then relapsed not to be able to go onto Lenalidomide as another option.		
Section 2 (the technology)	Surely there is also a high cost to the other treatments which require hospital visits and intraveneous drugs. Â Surely the cost of someone dying is also high in terms of NHS care.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)	AS in Section 2 above.		
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	It is wholly inappropriate to reject this drug on the grounds of cost. Â It is clinically proven: why should patients be allowed to die when a drug can help prolong their life and improve drastically that quality of life. Â No one should have to endure this. Â The drug manufacturers, NICe and DH could find a solution to make the drug more cost effective. Â Not to do this is unreasonable and unjustifiable, and contrary to the principles of the NHS Act. If NICE does not reconsider its recommendation, patients will be denied this very important drug, which represents a huge advance in		

	the treatment of myeloma: we should be moving forwards, not backwards. NICEs consultation on the treatment of rarer diseases through more expensive drugs is welcomed: this consultation should apply to revlimid.
Section 2 (the technology)	The balance between clinical effectiveness and side-effects is excellent:patients can remain on it longer term. Â Further, it is a convenient treatment for patient and their families, and does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments. This benefits both patients and the NHS. NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments. The drug also offers substantial benefit to patients as it increases the number of therapeutic options available, meaning more patients in remission, improving their overall survival and helping them lead an increasingly independent life. Following the review of the "top-up" regime, patients can now pay themselves if the NHS does not provide the drug. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. "Topping up" will thus lead to a two tier health system for myeloma patients - again this is unjustifiable, unreasonable, and contrary to the principles of the NHS.
Section 3 (manufacturer's submission)	The manufacturer should discuss with NICE and DH how to fund a cost effective solution to the provision of this very important, clinically proven life enhancing grug.
Section 4 (consideration of the evidence)	This is unacceptable. Â Cost effective solutions can be found. Â An unwillingness to negotiate on the part of all parties is unacceptable and wholly unreasonable.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	This is too far in the future. Â Patients will die in the meantime. Â Find a cost effective solution now

Name	[redacted]		
Role	Carer		
Other role	daughter		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Lenalidomide has been shown to have significant benefits, even in those who have received prior therapy - in fact it works well as a final phase treatment - therefore NICE should recomment the provision of lenalidomide as advised by clinicians at any appropriate stage of multiple myeloma.		
Section 2 (the technology)	Whislt the debate over prioroity of expendiutre will be never ending the beneifts of this treatment have been shown to be significant. Â Therefore NICE should recommend its approval		
Section 3 (manufacturer's submission)	Please approve this treatment - it will prolong lives at an independent level		
Section 4 (consideration of the	So much progres is being made in the treatment of this disease - please approve lenalidomide to be used so that its benefits can be		

evidence)	felt.
Section 5 (implementation)	Conforming to these Implementation guidlines seems entirely appropriate for lenalidomide
Section 6 (related NICE guidance)	No comment
Section 7 (proposed date of review of guidance)	As a minimum this must be reviewed in 1 year - Oct 2009

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)	Lenalidomide is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions must be found to reduce its cost. Given the nature of the disease and the importance of new developments, I implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For me to know that there is a licensed, clinically effective treatment out there but that I cannot have it is a cross I should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for me to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and |I urge that any new reforms that come out of the consultation will apply to Lenalidomide		
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for me. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? I can self-medicate at home or at work NHS access to Revlimid would ensure that I have treatment options even when I am refractory to other therapies, and will help me live longer to benefit from future developments Newer treatments such as Lenalidomide provide substantial benefit to me in increasing the number of therapeutic options I have available to get back into remission, improving my overall survival and helping me lead an increasingly independent life		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)	In 4.13 i consider imminent death to be a factor to be considered. Most of us would do anything to SURVIVE		
Section 5 (implementation)			
Section 6 (related NICE guidance)	If I am forced to have bortezomib as my next treatment I will lose my job and will be unemployable. Have Nice got a guidance for that		
Section 7 (proposed date of review	Statistically I will probably be dead by then. With access to new treatments my consultant (whom I trust more than statistics)thinks I		

of guidance)	could survive even longer

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)	Myeloma is a disease where younger patients in particular, have to live with the knowledge of reduced life expectancy. By its nature, myeloma returns even after a period of remission. Revlimid is the first treatment to be developed where the balance between effectiveness and side-effects is good enough to allow patients to remain on it long term. It therefore is a worthwhile addition to the existing range of treatments and would help not only those who have relapsed, but also those currently in remission who can take comfort that an effective treatment will not be denied on the basis of cost when the inevitable relapse takes place. The drug is expensive, and whilst I am not opposed in principle to the idea of top up fees or making some contribution towards the cost of a drug, the governments new proposals would be of little help to the majority of NHS patients in this case. Surely, rather than merely rejecting out of hand a drug that fills a gap in the existing armoury, NICE the NHS and the drug companies should be helping patients (emphasise helping) by finding ways in which the drug can be made available at more reasonable cost, as has been the case with other drugs.		
Section 2 (the technology)	Although the exact mechanism by which it works is not understood, revlimid is licensed and has been shown to be effective. Likewise although side effects do exist they are sufficiently tolerable to allow patients to remain on this drug for longer than alternatives. Similarly it is relatively easy to take and allows some semblance of normality. Although it is a cliche to say that new treatments are being developed all the time, it is neverteless true in the case of myeloma. Stem cell transplants have recently been introduced and this sort of field can be expected to develop following the US election. It is important that patients have a range of conventional treatments available to keep them alive in order to be able to take advantage in future. Cost is an issue, however NICE and other parties should be helping to find ways to reduce costs not merely rejecting out of hand.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]
Role	Carer
Other role	

Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Myeloma is a rare type of cancer which may be a reason for the higher costs of effective treatment. Â It is therefore unreasonable and extremely stressful to suffers and their loved ones for NICE to seek to withhold drugs such as Revlimid which shows impressive results		
Section 2 (the technology)	Revlimid has been shown to be clinically effective and excellent in terms of its side- effects. Â It is convenient to administer as patients can self-medicate (cost-effctive). It will improve survival rate and it would be hard on patients and their families to know that treatment which could prolong the life of loved-ones are withheld on the grounds of costs.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Patients should not be denied a life saving drug solely on cost grounds. Ways must be found to save on waste which would enable this important drug to be made available to those in need. Patients know there is this drug available and to deny it is cruel and unforgivable. Nice should reconsider its attitude urgently so as to avoid patients having difficulty in accessing the drug. Revlimid -a drug so vital to affected patients - should be considered in the same way by NICE as it has approved higher cost treatments for other rare diseases.		
Section 2 (the technology)	Revlimid is effective and can be safely used over a long period. Revlimid is simple to administer in a home environment and avoids hospital visits - saving cost to both patients and the NHS. Revlimid is said to have little or no side effects making it ideal for independent and lengthened life. The cost per month to virtually all patients is prohibitive but, as part of general funding by the popolation as a whole, is minimal because of the relatively small number of patients needing this treatment. The NHS must manage waste - such as most patients witness in the every day running of hospital appointments systems, for example, and concentrate on essentials - such as this life saving drug.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			

Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	son of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	please make this availavel for my dad		
Section 2 (the technology)	my dad has paid into the NHS for years and should be given the drug when he needs it		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Please make this drug available to patients because it gives extended life expectancy with good quality of life		
Section 2 (the technology)	Most patients would not be able to pay over Â£4,000 per month and so it should be given to all on the NHS		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Please make this drug available to patients because it gives extended life expectancy with good quality of life		
Section 2 (the technology)	Most patients would not be able to pay over Â£4,000 per month and so it should be given to all on the NHS		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Please make this drug available to patients because it gives extended life expectancy with good quality of life		
Section 2 (the technology)	The majority of patients will not be in a position to pay over Â£43,000 for medication - it should therefore be provided by NHS		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment.		
Section 5 (implementation)	no comment.		
Section 6 (related NICE guidance)	no comment.		
Section 7 (proposed date of review of guidance)	no comment.		

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes	My Father is a Myeloma patient.		

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Point 1.1 Lenalidomide is now a front line treatment in the US it is so because it has been shown to be efficacious in prolonging life for a number of patients. I believe we need to work out effective payment systems with the manufacturer (like Velcade) so that we a) dont end up paying for the drug when it does not work for pateints. b)dont deny patients access
Section 2 (the technology)	2.3 Negotiated procurement is the way forward for certain. Perhaps a sliding scale of payment to the manufacturer based upon efficacy of treatment? Also- we are dealing with a small number of patients here. MM being a relatively rare cancer.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	4.13 The inadequate cost effectiveness can be overcome by agreeing a Velcade- style payment agreement with the manufacturer. Effort and concentration should be focused on the supplier relationship to this effect. This fine-tuning approach to payment could potentially be extended to other areas of NHS procurement with cost savings resulting. Perhaps we are all usefully involved in a process whereby NHS finance management in respect of consumables, including medication, is being fine tuned? This would certainly seem to be a need as we go forward. With a 110 billion projected budget in 2010, small changes in procurement policy could make huge difference in monetary terms of course.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role	nurse		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Rejecting Lenalidomide for the treatment of relapsed Myeloma purely on the grounds of cost, it has been shown to be clinically effective, is totally inappropriate. It should be a priority to make this treatment available to all (free to all at the point of delivery) by ensuring the pharmacutical companies renegotiate their prices. Not to do so is allowing them to put additional strain, both physically and finacially, on patients and carers who wish to get the best possible treatment for this awful disease.		
Section 2 (the technology)	It has been shown that patients tolerate Lenalidomide well and its administration is straightforward allowing self medication. Therefore it avoids hospital visits as required in intravenous treatments and is another valuble treatment option to achieve remission and improve the quality of life for patients. To see this treatment option "out there" but out of reach to someone like myself when needed, is torture. Topping up would be out of the question but for a very few and families such as mine would be made to feel guilty for not being able to afford "the best".		
Section 3			

(manufacturer's submission)	
Section 4 (consideration of the evidence)	As above
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	Revimid is a clinically effective treatment with impressive data supporting its use in myeloma. to reject it purely on cost alone is wholly inappropriate-solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient.		
Section 2 (the technology)	Revlimid is the first myeloma trearment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on longer term.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid has been proved to be effective in treating multiple myeloma. Â It makes no sense, clinically, to reject its use for those patients who have already received another therapy but who then need an alternative because of a recurrence of the disease. Â A failure by NICE to reconsider this draft recommendation will deny patients access to this treatment which could be devastating to patients when they know that there is a licensed, effective treatment which Â is not being made available purely because of cost. Â Cost has to be a consideration, but efforts should be made to ensure the manufacturer		

	prices the drug more realistically. Â One of the problems for drug companies is that they are expected to fully fund their drug research and then have to recoup the cost through drug products before patents expire. Â Why cannot the Government provide funding for drug research? I have a good friend who has only just turned 50, a mother who has been working full time but with a relapse now faces a bleak future without Revlimid.
Section 2 (the technology)	Revlimid has 3 big advantages over other currently available treatments for multiple myeloma: 1. There is an excellent balance between its clinical effectiveness and reported side effects. 2. It is convenient for patients and their families, being able to be taken orally at home or at work. 3. Â Oral dosing means Revlimid does not require visits to hospital for i/v treatment so reducing the cost and resource demands on the NHS of hospital visits. Revlimid does have a high cost but Myeloma is a rare disease so it will not need to be widely prescribed. Â If it can enable patients to return to a full productive life, it will be beneficial to the economy and society. Â To expect patients to pay for the drug themselves is totally unrealistic
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Health professional Â NHS Â Â Â Â RETIRED		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a Â clinically Â effective treatment with Â data to support its use in myeloma and is obtainable Â in Europe. Discussions should be Â held Â with Â the Â manufacturer to Â find Â ways Â to Â reduce Â the Â cost.		
Section 2 (the technology)	Revlimid has clinical effectiveness with few side-effects.The teatment will be Â more cost Â effective as it can be self-medicated and will enable the patient Â to lead a more independent life.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review			

of guidance)	

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)	Revlimid is a clinically effective treament with impressive data supporting is use in myeloma (M).To reject it purely on cost alone is wholly inappropriate-solutions can be found to reduce its cost.Given the nature of the disease & the importance of new developments, the M community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients. For patients to know that there is a licenced, clinically effective treatment out there but they cannot have it is a cross they should not have to bear.A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M.The rarity & severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK.The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out ot the consultation will apply to Revlimid.		
Section 2 (the technology)	Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for sayintravenous treatments-patients can self-medicate at home or at work. NHS access to Revlimid would ensure that M patients have treatment options even when they are refractory to other therapies, and will help them live longer & benefit from future developments. Revlimid offers therapeutic options for patients to get back into remission, improving their overall survival and helping them lead an increasingly independent life. The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per monthAricept (to treat early stage Alzheimers) costs Â£75 per month. Both are currently rejected by NICE. It is clear that were a treatment costs only a few pounds a day, topping up is unlikely to prove a serious financial burden vs. a treatment costing thousands of pounds a month & would be affordable to very few people. If Revlimid remains rejected by NICE, the financial burden on the vast majority of myeloma patients suitable for Revlimid would be unmanageable.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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)	Revlimid is a clinically effective treatment which could be of great benefit to patients and their families ! The rarity of myeloma and its cinderella position in the overall cancer picture should surely mean that all possible help must be given.		
Section 2 (the technology)	The balance between effectivenes and side effects offers great hope to patients that their life expectancy can be increased.To take away this hope on the grounds of cost seems indefensible.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (M). Â To reject is purely on cost alone is wholly inappropriate - solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M communityimplore NICR, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interest of patients. For patients to know that there is a licennsed, clinically effective treatment out there but they cannot have it is a cross they should not have to bear. A failure by NICE to reconsider its draft will make it increasinly difficult for patients to gain access to this important advance in the treatment of of M The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. Â The recently announced NICE consultation on apppraising higher cost treaments for rarer deiseases is extremely welcome, and we urge that any new reformds that come out of the consulation will aplly to Revimid. Revlimid is the first myelpma to be developed where the balance between clinical effectiveness and side effects is excellant, so tha tpatients can remain on it longer term. Revlimid is a convenient treatment, patients can dose themselves, not involving expensive hospital visits. Â The Government now say that patients can only pay for treatment (which they have already paid for by taxation) if the NHS cannot afford such drugs. Â Very few patients will be able to afford such costly lifesaving drugs thus denying them leave to remain on this earth and possibly costing the UK state far more in lost earnings by family		

	members. Revlimid offers therapeutic options to patients to get back into remission, improving their overall survival and helping them lead an increasingly indepenent life
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with Â impressivie data supporting its Â use in myeloma (M). To reject it purely on cost alone is wholly inapropriate - solutions can be found to reduce its cost. Â Given the nature of the diseases and the importance of new developments, the M community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of the patient
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side effects is excellent, so that patients can remain on it longer term. Revlimid can be administered orally by the patient thus reducing costly hospital visits. Revlimid keeps patients alive. Â The cost that patients may have to bear themselves of purchase of Revlimid will be beyond the reach of nearly all of them, and having already paid into the NHS via taxation, it will be a double financial burden
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	none		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in cases of myloma. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of the disease. Â If patients know there is a licensed treatment available it gives them hope.		
Section 2 (the technology)	NHS access to Revlimid awould ensure that myeloma patients have treatment options even when refractory to other therapies - it will help them live longer and be in a position to benefit from future developments. It is a convenient treatment for patient and their family as oral dosing does not involve the time intensive visits to hospital.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6			

(related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a new clinically effective treatment.It has been demonstrated in recent trials to offer a significant extension of time to disease progression and increased survival for patients who relapse. NICE should conclude that Revlimid be available as a treatment on the NHS. To refuse this drug on cost alone is appalling. It is necessary to talk to the drug companies to reduce the cost of Revlimid, learning from the risk sharing scheme that was introduced with the drug Velcade. The interpretation of QUALY also needs addressing. I urge NICE, the Government, Consultants, and the drug manufacturer to discuss ways for Revlimid to be available on the NHS. NHS access to Revlimid allows Myeloma sufferers to live longer in the hope of making this incurable illness into a chronic disease.		
Section 2 (the technology)	The introduction of co-payment may be good for some patients, however, for Myeloma sufferers finding nearly Â£5,000 monthly to stay alive will only add to their worries. Some patients because of the nature of the disease have had to give up work and probably survive on government finances like DLA or income support, where do they fine money to live? Think about it from their point of view. Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so Myeloma Sufferers can remain on it longer term. It is a more convenient treatment for Myeloma Sufferers. Taking the drug orally reduces the need to attend hospital and also cuts down other procedures like insertion of Hickman lines which costs the NHS		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary	Revlimid is clinically effective in the treatment of myeloma with data to support this. Advancements are being made all the time to combat		

recommendations)	rare cancers such as myeloma patients must be able to access these drugs on a fair unbiased basis. To refuse patients in England and Wales on the grounds of cost is morally reprehensable. These patients have paid into society for many years and the state should be there to aid them in their hour of need. This drug can be life changing for so many people, not just patients but families too, to know there is something out there that can help ease or put an end to your suffering and aguish and yet be just out of reach must be soul destroying. The powers that be, the government and NICE must broker ways of obtaining these essential cancer drugs at an affordable, sustainable rate. I am aware of how much the good people of this country offer by way of donations to organisations such as cancer reserch UK, that money is not for admin and bureacrats it is for cures and life changing drugs. For these drugs to be developed yet witheld from cancer patients would be a national disgrace.
Section 2 (the technology)	Revilimid is a fantastic breakthrough drug for myeloma sufferers as the is an excellent balance between its effectiveness and the side effects. The benefit of the drug being administered orally mean that people can continue to go about their everyday lives, with less time spent in hospital. I have read some literature on the up and coming top up scheme where patients can fund their own treatment whilst being seen by the NHS. I feel in some cases this will be beneficial, however in the case of revlimid the costs will finiancially cripple patients after just a few months. It will see a gulf of difference where the wealthy will survive and the less well off will remorgage and refinance everything they own just for a chance of survival. Surely our government, one of the world leaders will not allow this?
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	To refuse a cancer sufferer in England and Wales is immoral. This drug is approved for use all across Europe and in Scotland, how can this be fair. The NHS was established to be free at the point of need, these patients are indeed in need.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	relative of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is clinically effective, and the data that supports its use in Myeloma is solid. Â To make the decision on cost grounds alone is unacceptable - and morally wrong. Â As with other drugs, there are probably ways to reduce the cost to the NHS, and cost alone should not be used as a criteria for treating such a rare disease. Only by endorsing treatment with Revlimid, will further advances develop.		
Section 2 (the technology)	Revlimid is the first treatment for Myeloma where there is a good balance between the clinical effectivness and the side effects, allowing patients to remain on it long term. Â It is conveneient for patients because it does not need to be administered in hospital - and		

	therefore requires less of the NHSs resources. Â The increased life expectancy that Revlimid brings, may allow patients to benefit from other treatments as they are developed. Â Even if that is not realistic, it increases the chances of getting back into remission, increases life expectancy and gives longer independent life. Â While the Ministers decision to allow topping up of treaments, the cost of Revlimid means that very few patients would be able to top up their NHS treatment.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is clinically effective, so it is in the best interests of patients to reduce the price and make it available to all sufferers. For them to know that the drug exists and yet be denied it is unnecessarily hard. Any new reforms that come from the consultation on rare diseases should apply to Revlimid.		
Section 2 (the technology)	Revlimid offers the following benefits: excellent balance between clinical effectiveness and side effects. Â Patients can self-medicate at home, which is better for them and for their families. Patients live longer, thus allowing opportunities for further developments, where currently available treatments are unsuitable. Patients can lead more independent lives, and survive longer. Â However, top-up costs are so high that only the very wealthy would be able to afford the medication. Â Consequently, the vast majority of myeloma patients for whom the drug would be suitable would be denied Revlimid.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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)	Revlimid is clinically effective, there is a wealth of data to support this - to reject it on cost alone is wholly inappropriate. As with Velcade surely solutions can be found to reduce this cost and improve patient options for extending life and achieving remission. Revlimid is a licenced treatment and represents an important advance in the options available to myeloma sufferers. Myeloma is a rarer form of cancer and NICE has recently announced a consultation on higher cost treatments. Any recommendations on this need to be applied to Revlimid. There needs to be a review of this decision before people are denied the substantial benefits Revlimid can bring.		
Section 2 (the technology)	This is a convenient treatment, reducing the need for hospital visits, with an excellent balance between clinical effectiveness and side-effects. It would improve patient access to treatment options and they could remain on it for much longer. As life expectancy is improved refractory patients could benefit from other new developments by having their life extended with Revlimid. Given the current cost/month most people on ordinary wages would not be able to afford it as a top up.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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)	Revlimid is proven to be clinically very effective and to reject it on cost alone must surely be unfair and inappropriate. Surely a solution could be found to reduce its cost in a way that is acceptable to all parties as to a myeloma sufferer knowing that a life extending drug is out-there but unavailable is very hard to bear.		
Section 2 (the technology)	I understand that Revlimid the the first myeloma treatment where the balance between effectiveness and side-effects is excellent and this enable patients to remain on it longer and hopefully enjoy an independant lifestyle. Â Also being in tablet form makes it very convenient and avoids the usual hospital visits for intravenous treatments. Â Although the government has agreed that patients can top up treatment now, Revlimid is at present so expensive that few people will be in a postion to do so.		

Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	Revlimid works and can give not just a few months but many years with high quality of life. If the average is say 3 or 5 years then many with few complications might live for many years thus Myeloma can be treated as practically a chronic rather than an incurable disease. This should not be denied to patients		
Section 2 (the technology)	Having paid into NHS for over 40 years it would seem that I would be denied access to a drug that could take me considerably beyond my current 58 years with few side effects. The costs for the vast majority of patients would be impossible.		
Section 3 (manufacturer's submission)	The arguments above are very complex. All I would say is that manufacturers and the research they carry out needs a fair rate of return to enable the ongoing battle against cancer. Remember 1 in 3 is affected by cancer and no one is guaranteed to be safe. Research in the Myeloma area of cancer at the stem cell level can benefit many other cancers in the UK and patients world wide including the developing world. Restricting reasonable payment to research and manufactures can adversely affect us all in the long term.		
Section 4 (consideration of the evidence)	From my observation, I am seeing more and younger patients e.g. 41 years and 36 years in the last month. Whilst there might be many older people getting Multiple Myeloma, do not forget that there are many younger patients with younger families. Good treatment for younger patients means that they get back to work and pay more taxes rather than stay ill and rely on benefits. This becomes more significant as survival with good quality of life increases.		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Since it has been shown in clinical trials that Revlimid is an effective and important treatment for myeloma it seems unreasonable for it to be rejected for its cost.The Government together with the drugs companies must be able to bring the price within range of the NHS for the benefit of all patients who through no fault of their own suffer from this rare cancer.
Section 2 (the technology)	Although, as with many drugs side affects can occur, revlimid has shown to be well tolerated enabling patients to remain on it for longer periods and as it is taken orally, self-medication is possible eliminating the cost and use of hospital resourses.In this way patients are able to experience a more normal way of life which in turn can releve them of the depression so often felt with a condition such as myeloma.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	The clinical data currently available about this drug is most impressive - I am testament to this - therefore to reject the drug on cost alone is compeletely unacceptable - I feel most strongly that something could, and must be done, possibly an agreement between NICE and the pharmaceutical company, to bring the cost of the drug down so that more myeloma patients can access at the point of clinical need. For myeloma patients to know that there is a fully licensed, clinically effective treatment available to treat myeloma but for it not be made available to them is completely unacceptable - it is even more unacceptable when one considers the main reason behind the decision not approve is cost - its almost barbaric! Myeloma is a relatively rare illness - this can present additional challenges in terms of trying to access vital treatments therefore I think it is vital that any formal outcome (reform) emerging from the recently announced NICE consultation on appraising higer cost treatments for rarer cancers also apply to Revlimid. Finally, it is also difficult to overestimate the impact on a myeloma patient and their loved ones of being refused a life-saving treatment.		
Section 2 (the technology)	Revlimid is a very exiting drug in the treatment of myeloma - its ability to effectively treat myeloma as well as produce minimal side-effects in patients compared to other and more traditional chemotherapies is particularly relevant to patients and also their carers.		

	In a disease like myeloma it is crucial for patients that as many different treatment options are available, especially for those patients who are no longer responding to other treatments - the drug can provide a lifeline! In those myeloma patients who respond - and many myeloma patients are testament to this - the drug not only increases life expectancy but also increases the chance of patients being able to benefit from other new treatments currently being developed. It can also be argued that Revlimid is a convenient treatment - patients are able to self administer therefore the number of hospital visits involved during treatment are considerably reduced thus saving money for the NHS.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Patients wife		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	The committees recommendation NOT to approve the use of Lenalidomide on cost alone is very unfair. Because Myeloma is a rare cancer it is much more difficult for drug companies to recoup development costs but surely some compromise can be reached as it has been with the use of Bortezomid. To leave the decision for allowing this treatment in the hands of the local PCT does not provide a consistant approach and means decisions of life and death are decided by a group of bureaucrats who often do not have haematological expertise.		
Section 2 (the technology)	My husband is now into his 4th month of Revlimid. Having been turned down by our PCT for funding and with our appeal unsuccessful our insurance company agreed to 6 months funding. Paraprotein levels have dropped to insignificant and side effects are so much more manageable than when on Bortezomid. He needs only to attend the clinic once a month instead of twice a week and quality of life could almost be considered normal. In 2 months time when our funding comes to an end we will have to resume battle with the PCT with no hope of success. For my husbsnd who has a performance status of zero this will indeed add stress and uncertainty at a time when he is entitled to feel secure in the knowledge that the best and most appropriate treatment is available to him.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the			

evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	The decision is unfair in that efficacy is proved and the decision is based therefore purely on cost.		
Section 2 (the technology)	Serious side effects can be controlled with low-cost treatments e.g. aspirin. The overall cost of treatment seems to be in line with other treatments.		
Section 3 (manufacturer's submission)	There can be no doubt that the treatment is effective.		
Section 4 (consideration of the evidence)	Surely if cost is the only factor in this decision you are denying people such as myself the opportunity to relieve symptoms and also live longer. It is your responsibility to meet with the manufacturers and find a solution to this problem rather than condemning patients to an earlier death.		
Section 5 (implementation)	No comment.		
Section 6 (related NICE guidance)	No comment.		
Section 7 (proposed date of review of guidance)	The technology is proved the issue is cost and therefore the review date should be as early as possible to reflect this.		

Name	[redacted]		
Role	Patient		
Other role	Health professional		
Location	England	**Conflict**	no
Notes	Inspite of having myeloma, I am presently still able to work as a community midwife, employed by the NHS		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	The failure by NICE to recommend this treatment will make it increasingly difficult for patients that need this treatment, to access it. It Â is an important advance in the treatment of myeloma and availability of drugs is limited. Â It is very unsettling to know there is an effective treatment available that may be denied to patients in this country, but would be available elsewhere. Â I feel solutions could be found to help reduce the cost and discussions to this effect should take place between NICE, the government and the manufacturers to ensure that this can happen. Â It seems to be extremely unfair that the rarity and severity of myloma is overlooked and this is not taken into account when looking at the overall cost. The recently announced NICE consultation on appraising higher cost drugs for rarer diseases		

	is welcome and I urge that any new reforms that come out of the consultation will apply to Revlimid. Â As a myeloma patient, in remission at present, I can assure the committee that this is an unpleasant disease with no known cure. Â Please dont reject our opportunity for a longer life. Â I was only 51 at time of diagnosis.
Section 2 (the technology)	Revlimid is the first treatment to be developed where the balance between clinical effectiveness and side effects is excellent meaning that patients can remain on the treatment for longer. Revlimid is convenient as oral dosing means patients can self administer thereby reducing costly hospital visits. Access to Revlimid would ensure treatment would be available when others had failed and that we may live longer and be able to benefit from newer treatments as they become available. Revlimid Â can provide substantial benefit to patients by increasing the number of therapeutic options available to increase possibilities of remission, improving survival and allowing an independant and useful life.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role	retired		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	The person for whom I care has received Revlamid treatment as part of a clinical trial, with excellent results. Â Why would the result of Revlamid treatment be any less effective for other Myeloma sufferers?		
Section 2 (the technology)	Revlamid side effects seem to be no better and no worse than those caused by any other Multiple Myelomo treatment. Â However, its results are far better.		
Section 3 (manufacturer's submission)	The clinical effectiveness of this drug is proven.		
Section 4 (consideration of the evidence)	Revlamid is easy to use, far better tolerated than Velcade so did not impose a particular hospital visit regime. This made treatment much easier and more tolerable for the patient. Â It can be taken with low doseage Dex. which is the principle drug for horendous side effects meaning better tolerance. Â Regarding cost - what price would you put on extending your relatives life? This drug is not just for a short life extension but for remission of three years or more insome cases. The longer the remission period, the higher the likelihood for some other life prolonging treatment to be developed. Currently US trials are using a combination of Velcade and Revlamid as a new therapy - why not here? You are urged to use your new powers in reappraising this drug as Mike Richards recommends. Â Topping up is unfair for those patients who cannot afford to pay and contadicts the original purpose		

	of the National Health Service. Â To deny people life extending drugs is obscene and not worthy of our society. Â Â In light of Prof. Richards recommendations to the Government, NICE now have a responsibility towards appraisin
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	Given the nature of progress of this awful illness, many of those people who are respondees to this consultation will not be respondees in 2011. Â This seems a rather dramatic way of dealing with those who disagree with your findings.

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	The rarity and severity of myeloma brings with it a number of challenges for which there are currently no formal ways of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and I would hope that any new reforms that come out of the consultation will apply to Revlimid. I believe this is particularly pertinent given the fact that Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma.		
Section 2 (the technology)	The combination of the adverse event profile of Revlimid and the efficacy of the drug makes it an excellent treatment for myeloma. Â Given the fact that it is an oral treatment that can be self administered, the resource burden to any public health system is also reduced. Â The overall cost of the drug would however not be affordable to the vast majority of patients for whom Revlimid is a suitable treatment.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	other		
Other role	Daughter of a myeloma patient, living away from parental home		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's	There have been a handful of novel therapies developed for multiple myeloma over the past five years (where there were none in the prior		

preliminary recommendations)	30 years), of which lenalidomide is one. By my understanding, use of these novel therapies is bringing us to the point where myeloma can be regarded as more of a chronically controllable disease, rather than as the critical and intransigent one it once was. As the daughter of a patient diagnosed in the last six months with multiple myeloma, it is extremely disappointing to discover that my mother may not be offered lenalidomide simply because of cost issues, even though it could offer her real hope for a manageable life with this disease. Â It is particularly disillusioning since my mother is a nurse who trained and worked in the NHS for many years. I would urge NICE, the Government and the manufacturer to enter into discussions to agree a pricing model for lenalidomide which will allow this treatment to be made available to myeloma patients through the NHS.
Section 2 (the technology)	In a recent lecture given by Dr Shirley DSa (of Mount Vernon Hospital, Middlesex) it was stated that derivatives of thalidomide, such as lenalidomide, are of the order of 100 times more potent than thalidomide in their action against myeloma cells and yet are seen to result in lesser side-effects. As a result, lenalidomide is regarded as a useful, effective and sustainable treatment for myeloma patients. My mother is currently receiving a combination of thalidomide and dexamethasone, and was initially treated additionally with cyclophosphamide. The deterioration I witnessed in her condition over the course of just one cycle of this initial regime was devastating. Withdrawal of the cyclophosphamide returned her to a more stable position. From my whole family?s point of view, we want to know that my mother is being given the most effective treatment against the disease that will not itself shorten her life. To learn that lenalidomide has this combination of efficacies and yet that it will not be made available to her is very difficult. Both my parents have worked in not-for-profit roles in the local community and they simply do not have the resources to top up.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	This drug has been shown to be effective. It would be the next drug of treatment for my husband when he relapses.It should not be denied on grounds of cost when a solution could be arranged as with Velcade		
Section 2	Side effects are no worse than with other treatments.Treatment is oral		

(the technology)	and patient can get on with life the quality of which is vastly improved
Section 3 (manufacturer's submission)	Surely a compromise can be reached as with Velcade- that way trials carry on on on a bigger scale and myeloma patients get their fair share of the money available to cancer patients
Section 4 (consideration of the evidence)	New drugs should be given a chance how else will medicine progress?Myeloma may be incurable now but Revlimid offers the chance to turn it into a chronic but treatable illness -and that is life enhancing to patients such as my husband
Section 5 (implementation)	Because of local decision-making processes some patients already have problems with what is called the "post code lottery". We need to have a nation-wide policy for access to drugs. if the situation were not so complicated there would be no need for "guidance" in application
Section 6 (related NICE guidance)	These publications now reflect past successes -we need to be gearing up for the future, making myeloma a chronic treatable illness by giving Â the use of Revlimid a chance
Section 7 (proposed date of review of guidance)	How many patients will have died between 2011 and now if the chance Revlimid is denied them? Developments are so fast in todays medical world. For some patients Rev. is their last chance NOW

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)	This is the second time that myeloma patients have been in this situation. We have already faced a struggle to get access to Velcade on the NHS. Velcade was also rejected by NICE due to cost. It was later approved after many months of tireless campaigning and a price reduction scheme was proposed by the manufacturer. During this time, however, many suitable patients did not get the chance to try Velcade. We do not want to have to go through this long drawn-out process again. Myeloma patients are already experiencing difficulty in accessing Revlimid through local decision-making processes. Recent studies have shown that the introduction of novel treatments over the last decade such as Velcade and Revlimid has had a positive impact on both the survival and quality of life of myeloma patients. As a myeloma patient, Revlimid will offer me a treatment that is oral, easy to use, does not give me awful side-effects and lets me get on with my life with minimal disruption.		
Section 2 (the technology)			
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	Dear Sir/Madam, Revlimid has been clinically proven to be effective in treatment for myeloma. Â Although it is expensive, there are not many sufferers from this very serious and incurable disease, so the overall cost would not be that high. Â The cost to individual sufferers would, of course, be prohibative. Surely if patients can be kept well, needing less hospital treatment and Â fewer admissions that in itself makes it cost effective? Â Besides which this is a drug which can be taken by mouth and therefore administered at home. Â This is more straightforward and cheaper than drugs which must be administered intravenously. Besides being clinically effective, this drug causes less unwanted side effects than others used in treating this disease, enabling patients to use it over a longer period of time, saving on other treatment costs. Life is not easy for sufferers like myself, and it is made evan more difficult when we know that effective treatments are being denied to us, especially when theu are widely available in Europe and America. Â Perhaps there should be a seperate set of considerations for this and other rarer cancers/diseases, as the general rules seem unfair in these cases. Â Is there perhaps scope for negotiation with the drug companies? Yours sincerely [redacted].		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	This treatment is proven to be clinically effective, and if patients already on treatment are allowed to continue, why should it be denied to others?		
Section 2 (the technology)	This treatment has less side effects than mosr others currently used, and can therefore be tolerated for longer.		
Section 3 (manufacturer's submission)	No comment		
Section 4 (consideration of the evidence)	No comment		
Section 5 (implementation)	No comment		
Section 6 (related NICE guidance)	No comment		
Section 7 (proposed date of review of guidance)	No comment		

Name	[redacted]		
Role	Carer		
Other role	Husband of MM sufferer		
Location	England	**Conflict**	no
Notes	My wife was diagnosed 2 years ago with MM and she has undergone		

	VAD resulting in 10 months remission, followed by 6 Â Velcade treatments resulting in full remission - lasting just 3 weeks - we are now about to start on Thalidamide - it being the only sensible available treatment regime available to us on NHS whereas Lenalidomide would we are advised offer a better chances of longer remission.Living in Oxfordshire the Postcode Lottery rules this option out we are told by consultant at John Radcliffe - Oxford/Horton Hospital- Banbury Banbury.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Treatment of this rare disease by this clinically proven drug should be available to all those who are considered suitable for its use by there consultants. Rejection on cost alone is a travesty of justice to those needing it and paying their contributions to the NHS. Those of us caring for patients should not have to bear this knowledge that our loved ones lives depend on cost effective treatment when suitable treatment is licensed but considered too expensive. This is an important breakthrough in treatment of this disease and should not be refused to those few members of the population who require it. Further discussions must take place to reduce the cost of this treatment to the NHS.The rareity of the disease no doubt reflects the high cost as there is no "bulk" sales to recover costs.However just because an innocent person contracts a rare disease they have no control over should they should not have to suffer due to funding issues - overall the costs will be low due to low numbers of uptake in the NHS overall budget. As a husband who has just left his wife in a poor health to come to work knowing there is a proven solution available to some but not my wife I am devastated.
Section 2 (the technology)	* Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Â Â * Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work Â Â * NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Â Â * Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life Â Â * The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden. However, where the treatment in question costs thousands of pounds every month, such as Revlimid, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable
Section 3 (manufacturer's submission)	
Section 4	

(consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	We understand that Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone must be wholly inappropriate ? there must be ways to reduce its cost. Given the nature of the disease and the importance of new developments, we implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it, is devastating. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma. The current death sentence of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid.		
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, with the possibility of longer term treatment. Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work so less burden for NHS staff. NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life . No doubt you have read these copied words many times before. However surely the cost of this treatment is cheaper than the cost for the NHS of caring for terminally ill patients as they die over a long period?		
Section 3 (manufacturer's submission)	If this drug isnt supported, then it wont be improved. From the research and expert comments published to date it appears that there is a real possibility that this drug can take the illness from terminal to serious. So if it isnt supported, then arent you condemning these people?		
Section 4	Since the husband of a colleague developed this illness, I have heard		

(consideration of the evidence)	of increasing numbers being diagnosed. It seems to me that this illness is finally being recognised by some doctors but how many more people have it without correct diagnosis? The cost recovery of new drugs bears direct relation to the original R&D which makes me wonder if the base numbers of those who are really suffering from the disease is correct. If they are significantly higher then the cost recovery ratio changes and makes the drug a more acceptable cost since it would appear that the NHS balances life to cost.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	We urge the Appraisal committee to overturn its preliminary recommendation that REVLIMID (Lenalidomide) should not be made available on the NHS purely on cost despite the fact that it agreed the clinical evidence is strong. Recent studies have shown that this break through drug with impressive data supporting use in myeloma gives new hope to myeloma sufferers with a positive impact on survival and quality of life. The heartbreak for patients and families to know there is a licenced and clinically effective treatment for them but denied by the Governments policy directive to NICE the rationing body is I assure you unbearable. If price is the barrier to Revlimid being approved, a formula for pricing needs to be put in place by NICE, the Government and the manufacturer(Celgene) to make it affordable to the NHS. Myeloma presents many problems for patients and their families for which in the UK there is currently no formal way of dealing. Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness & side effects is excellent.It is in capsule form and does not involve costly time intensive visits to hospital.		
Section 2 (the technology)	Revlimid is an important advance in the treatment of Myeloma and we implore NICE to apply any new reforms to Revlimid when the new consultation appraising higher cost drugs takes place & uphold Mike Richards new report. The unfair and divisive Government policy allowing NHS appointment of 150 PCTs with multiple decisions including whether a patient with rare cancer receives expensive life saving drugs is wasteful.Cutting this bureaucracy and other NHS waste would release finance to fund the relatively few who need them (4000 a year) giving maximum therapeutic choice to get into remission live longer & benefit from future developments.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5			

(implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	While I am pleased to hear that patients currently receiving lenalidomide will be able to continue treatment, I urge NICE to make this drug available when appropriate to new patients. Although the disease is both rare and indeed very serious it does respond very well to this therapy even when other drugs have failed.		
Section 2 (the technology)	I urge NICE to reconsider its decision.This drug is proven to be clinically effective. I myself have been fortunate enough to benefit from it. I took Actimid and then Revlimid from March 2003 until October 2007 enjoying complete remission until October 2006. This long remission without any side effects enabled me to lead a completely normal life and to carry on working. I was not a burden to the NHS and all my treatment was as an out patient with just one monthly visit to the hospital. I fervently hope that other sufferers will be able to benefit from this wonderful drug and that all the research which has gone into producing it will benefit other sufferers. Surely it must be possible to negotiate ways of covering the expense? Why develop a drug if it cannot benefit the patient?		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)	Speaking as a patient and from personal experience,I cannot over emphasise Â the difference between Velcade and Revlimid in terms of their side effects. The effects of Velcade were significant and the drug was not effective. Revlimid quickly and efficiently produced total and long lasting remission without any side effects.		
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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 are people who have had a previous therapy,excluded from enjoying the benefits of Lenolidomide ? Â Myeloma patients regularly suffer at the hands of NICE simply because we are affected by a "rarer" cancer but in addition many of us would now be excluded on the basis of previous treatment irrespective of how successfull a new		

	drug could be in comparison to what was available/standard practice earlier in our cancer journey.
Section 2 (the technology)	When will NICE sit up and take notice that a Myeloma patient already has a huge cross to bear as it is currently incurable and then you knock us back time and time again with the cost ! Are you expecting us to lie down and play dead because we totally see your point that we are not worth Â£xxxx. Cant you see how agonising it is to read about the thousands being spent to treat obesity when a large % is self induced and yet cancer patients are denied expensive drugs for a condition that no-one on earth would engineer for themselves.
Section 3 (manufacturer's submission)	cost, cost, cost again.
Section 4 (consideration of the evidence)	Has the "buy now, pay later" scheme as with Velcade, been fully explored for this new therapy ?
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	This will sadly be too late for so many sufferers. Why on earth would you reschedule in this manner for a "life saving therapy" as opposed to a "life enhancing therapy".

Name	[redacted]		
Role	Carer		
Other role			
Location	Scotland	**Conflict**	no
Notes	My husband died on 27th october 2008 from multiple myeloma after being diagnosed with this disease on 22nd november 2002. I just wanted to say that he was in process of receiving thalidomide for second time after relapse of condition an wonder why people from scotland are not aware of this treatment.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	why when people are dying are these treatments not available and there are so many barriers to overcome. my husband was only 40years old when diagnosed and died after an enormous fight to survive.His consultant never ever mentioned this treatment was available, so there was no option to consider.		
Section 2 (the technology)	Why dose medication to keep people alive have to be at the cost of people dying because of cost to the NHS.		
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]
Role	Carer

Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Why would you want to deny a life saving drug for my husband. Please make it available.		
Section 2 (the technology)	My husband and I have paid into the NHS for 40 years. We have had good health for most of our lives until very recently. We have not been a drain on the NHS. Now we have a need to Â benefit we (My husband as a patient and me as a carer) are being denied to a life saving drug. This denial not only affects my husband but also me as a carers and our family.		
Section 3 (manufacturer's submission)	no comment		
Section 4 (consideration of the evidence)	no comment		
Section 5 (implementation)	no comment		
Section 6 (related NICE guidance)	no comment		
Section 7 (proposed date of review of guidance)	no comment		

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes	My husband has Multiple Myeloma and if NICE hadnt FINALLY given permission for the use of Velcade last November - he would now be dead. Lenilidamide would be his next treatment if and when his disease recurs.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Why? You are not there to work out economies - the E in the title of NICE Â is for Excellence! It is up to the SHAs and the PCTs if they can afford it. Myeloma is such a small (in terms of numbers) cancer. Most PCTs are likely to have only a few of patients.		
Section 2 (the technology)	ALL anti cancer drugs have side effects, slight or severe, and all patients are appraised of this when offered the treatment - it is up to them and their clinicians to weigh the options in the balance and then decide yes - or no.		
Section 3 (manufacturer's submission)	Once again - it works Â but it costs - not your remit to decide if it can be afforded		
Section 4 (consideration of the evidence)	Here we go again - it works!!!! Cost is not your problem!		
Section 5 (implementation)	Of what?! You are saying NO		
Section 6 (related NICE guidance)	You finally said yes to Bortezomib - that also works - my husband is alive to prove it! Why stop there - lenalidamide is needed, it is more effective thatn thalidomide. (currently used as maintenance for Multiple Myeloma)		
Section 7 (proposed date of review of guidance)	Please recruit a heamatologist to your panel - you maight have come to a different conclusion.		

Name	[redacted]		
Role	Patient		
Other role	Patient representative		
Location	England	**Conflict**	no
Notes	I am among the longest lasting Myeloma patients (16 years). My quality of life is second to none. I am a fully productive member of society. I have had Thalidomide, Bortezomide, and Lenalidomide (two at manufacturers expense).		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	You are WRONG in 1.1. Â Lenalidomide should remain a trial drug, and should only be available to patients for whom no other drug can prevent the symptoms of decline shown by each patient individually. Your wording implies it might be applied to new Myeloma patients. I cannot imagine you meant this to be so, as good statistical evidence on immediate side affects and possible future side effects is very restricted due to limited time and previous trial patients. Â There is no statistical manipulation that can reliably forecast this type of information. It should remain a trial drug (it costs too much to be otherwise) and should not be given to new patients, except on restricted and controlled trial basis, until such time as it can achieve routine status when fully tested. You are RIGHT about 1.2, but should not imagine this will materially effect the overall NHS costs, for the number of benefiting patients are likely to be lamentably small, especially in view of the characteristics of the Myeloma population. A few cycles can give complete remission, and yet the patient is unsuitable for future maintenance.		
Section 2 (the technology)	2.1 Â I quote "mechanism of action of lenalidomide is not understood". You have said it yourselves! Therefore the drug must remain on trial. One patient lost a gall bladder during cycle four. That patient was hopitalised with a fit immediately after cycle four. No one knows if this was a side effect. We must test and record if we are to clarify such results. With Thalidomide and Bortezomide, patients had neuropathy before the term was in use by doctors, dose reduction was unknown at the time. Neuropathy is now minimal with Lenalidomide. An aspirin a day prevents most blood clots with Lenalidomide. 2.3 is a travesty of actual drug costs. It only takes one or two cycles to exclude the 30% non respondents. It takes a third cycle to knock out most partial responders (another 30%). By the third cycle it is also obvious if the patient is in the top 30% of total responders, and very few patients seem to need more than 4 cycles.		
Section 3 (manufacturer's submission)	Myeloma patients are outstandingly different in individual response, so combining this with small sample sizes make comparisons meaningless. Any statistical significance becomes suspect with unknown variabilities. Most Myeloma treatments are only effective once, and all treatments only give a limited period of life. Therefore every additional treatment becomes essential for extending life, but only for a minority of patients. Even if Dex were twice as good as Lenalidomide, it would still be essential to keep both drugs in the doctors armoury. The cost has to be compared with survival expectancy and quality of life for EACH INDIVIDUAL patient. Using QALY for Myeloma is a travesty, for individual variation spreads from normal, to wishing for immediate death. Â A few have had every treatment, and luckily for some quality of life is still way above		

	average for the normal population, yet alone Myeloma. You are instigating major quality changes by your decisions. These quality changes are very adverse on those with the most to gain or to lose, as we desperately fight for our right to life.
Section 4 (consideration of the evidence)	There is not much left to be said after para 4 is read. Clearly you know the conclusion you must reach, and you twist the statistics to reach that conclusion. "There are lies, damned lies and statistics!" You do our nation a disservice with your QALY and your costings. Â They would appear to be a blind simply to cover the political necessities. I have proposed elsewhere that all these new drugs should be treated on a trials basis, with a finite annual sum for each drug, thus controlling costs. Â This would allow us to regain some credibility for drug research in this country. It would return the life saving decisions to doctors, and remove the administrators authorisation to dole out death sentences to patients. This of course is outside your remit, and you may therefore close your eyes to it.
Section 5 (implementation)	"Implementation advice on how to put the guidance into practice and national initiatives which support this locally." This implies you do have the authority to put forward a case for change. I propose you recommend a need to retain trial status for drugs, and carry out NHS formulated trials of all new drugs, using controlled budgets that determine whether 10, 100, or a 1000 trial patients are given access to a specific drug. This would replace your present blind refusal to accept any new drugs. This might even allow you to continue in existence after the next government comes to power. Â You need to do something to raise your credibility with the older population.
Section 6 (related NICE guidance)	Administrators can never improve outcomes. This is a task for doctors, and they cannot do it while your organisation follows its present policies. Bortezomib and Lenalidomide are comparable in methods and results. They are alternatives for individual patients, and no one will discover why, except in so far as the first world countries are continuing to investigate these drugs. Have we joined the third world? Improved outcome in Myeloma will only come with controlled availability of both drugs, and all other future drugs.
Section 7 (proposed date of review of guidance)	There will be nothing to review because no one in England will have any local knowledge on which to base any decision.

Name	[redacted]		
Role	Local government professional		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)			
Section 2 (the technology)	Cost should not be an impediment to treatment by the best means possible. The charge made for this treatment is unethically high and steps should be taken as a matter of priority to reduce this whilst allowing the manufacturer to make a reasonable return		

Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes	Professionally, Im a journalist. As I type, I have no intention of using the media.		
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)	I am horrified and gutted to the core at the decision that "the Committee concluded that the use of lenalidomide for the treatment of multiple myeloma in people who had received at least one prior therapy was not a cost-effective use of NHS resources". Having studied Social Policy at LSE, Im completely aware of the need for effective use of funding, but what youre forgetting is the nature of myeloma - its incurable and therefore the value placed on each year of survival is much, much higher than illnesses which have hope. It is for this reason that beesech you to change your recommendation on this. My dad has recently been diagnosed with myeloma and I experience a miracle every day that I get to see his smile. Knowing that his time will soon be up, I cant tell you how much three years would mean to me - its simply indescribable. Although were an honest, hard working family whove always paid our taxes, never gotten in trouble with the law and never claimed the dole, theres no way we can afford to pay for it ourselves, as offered by recent changes in the NHS. This absolutely, 100% needs to go through - anyone with a conscience should be able to see this.		
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
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)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

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)			
Section 2 (the technology)			
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)	A subgroup of patients should be considered separately from others. Namely, patients responding to thalidomide who become intolerant of this drug are likely to form a distinct subgroup of Thalidomide-treated patients with lower costs per Lenalidomide-gained QALY. Patients moving from Thalidomide to Lenalidomide usually do so after failure of the former. Having failed Thalidomide, such patients are more likely to fail Lenalidomide and thus have a higher calculated cost per QALY gained. By contrast patients responding to Thalidomide (who have to stop it because of toxicity) are probably more likely to respond to Lenalidomide (given that the two drugs are likely to function against myeloma in a similar way). The side effect profiles of the two drugs are distinct and a switch from Thalidomide to Lenalidomide for reasons of toxicity is reasonable. This is particularly true for side effects such as peripheral neuropathy (much more likely with Thalidomide).		
Section 5 (implementation)			
Section 6 (related NICE guidance)			

Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role	Friend of patient		
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)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	I was diagnosed with Multiple Myeloma in May 1992. Â Luckily my disease is responsive to many of the medications which I have received over the past six years. Â I was initially treated with VAD followed by stem cell transplant. Â Following my relapse my treatment has been with Thalidomide, firstly on its own, then in combination with Cyclophosphamide and Dexamethasone. In July 08 I was prescribed Velcade in combination with Dexamethasone and completed four cycles. Â Currently my disease is at a low level but I am suffering very painful peripheral neuropathy. Â As a retired research based engineer I have maintained an awareness of the developments in the treatment and management of Multiple Myeloma.		
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)	I am concerned that NICE is examining the statistics of Multiple Myeloma as a single population of patients. Â I appreciate that statistically the number of Multiple Myeloma cases in the UK makes in-depth analysis difficult. However, by treating all Myeloma patients		

	as a single population you will come to some very misleading conclusions. Â The division of population within Myeloma patients that I think is most relevant to the current conclusion is: a) Patients whose Myeloma is responsive (slow relapsers) and therefore have a good chance of living for some years: b) Patients whose Myeloma is unresponsive and who therefore have a poor chance of survival. Â For the unfortunate patients whose Myeloma does not respond to most treatments, Revlimid might offer little advantage over Thalidomide. Â However, for those patients whose Myeloma is responsive to treatment and where the treatment period is likely to be extended over a long period, Revlimid is a clinically effective treatment which potentially offers a vastly improved quality of life. Â I appreciate that quality of life is difficult to measure or compare to other factors but this is why the decision should be left to the individual physician. I believe that the use of Thalidomide early in the treatment cycle brings new risks for those patients whose Myeloma is responsive to treatment (slow relapsers) and therefore have a good life expectancy. Â For example it brings a high risk of peripheral neuropathy, which decreases the patient?s tolerance to treatment by other drugs. Â Consequently the one bright star on the current horizon is Lenalidomide. Â Revilimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side effects is excellent. Â The use of the current reliance on Thalidomide will lead to a higher proportion of patients with a poor quality of life due to painful peripheral neuropathy. Â For those patients whose Myeloma is difficult to treat this may not be a relevant issue since sadly their life expectancy is shorter. I am very supportive of NICE in trying to reduce the price of drugs but disagree strongly with the way NICE is looking at the advantages and disadvantages of Revlimid and by ?lumping all? patients together. Â The population of patients who are slow relapsers, with good life expectancy, must be treated statistically separately to those whose disease is unresponsive to treatment. Â In the case of slow relapsers the current conclusions of NICE are not valid since ?Revilimid? would likely have a more prolonged benefit. Â On behalf of my fellow Myeloma patients I would press you to look further at the point I have made here. Â Since Myeloma is such a complex disease, I would prefer treatment options that are flexible and that do not lead to the patient being in constant pain and where the physician has the maximum discretion. As one of many Myeloma ?sufferers?, I know that there is a clinically effective treatment available that we may not be able to have. Â We also know that it is because in ?some cases? it might not be cost effective. Â This is a cross that most of us would be unhappy to bear. Â Revilimid can be a saviour to many patients and one day a decision against it would be seen as an extremely retrograde step.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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 (the technology)			
Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)	NICE should investigate innovative ways of reducing the cost of this treatment, so that patients who would benefit from the treatment can be offered an affordable drug, either NHS or self-funded.		
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	other		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes	A concerned friend.		
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)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	My father suffers from myeloma.		
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)	It is my understanding that lenalidomide has been given marketing approval by the European Medicines Agency (EMEA) for use in combination with a standard therapy, dexamethasone, in patients who have received at least one prior treatment. It is not acceptable that the standard of NHS treatment in England has fallen way below that of Europe in the treatment of cancers. I urge NICE and the drug companies to come to an agreement in this case, similar to the outcome of Velcade, where patients showing minimal or no response will be taken off the treatment and the manufacturer will be liable for the cost. This would provide a cost effective solution for the PCTs as well as offering valuable time and quality of life to those suffering with myeloma.
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	I urge all reviews to take place as soon as is possible as current patients of myeloma are being affect, and dying earlier, while this issue remains unresolved.

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, & we urge that any new reforms that come out of the consultation will apply to Revlimid		
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital? patients can self-medicate at home or at work		

	NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Revlimid offers therapeutic options to patients to get back into remission, improving their overall survival and helping them lead an increasingly independent life The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden vs. treatment costing thousands of pounds every month, will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, & we urge that any new reforms that come out of the consultation will apply to Revlimid		
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Section 3 (manufacturer's submission)	When the National Insurance Acv and the National Assistance Act was introduced at the end of the second world war it was noted that: For a long time doctors and others who have studied the subject of medical care have felt that a national medical service was essential to make the best use of hospitals in each area and to bring the full range of modern medicines within the reach of everyone. Hence the NI Act and NA Act were born. Â Â It was to meet this and other needs that the National Health Service Act was passed in 1946. Ref: Pears Encyclopedia. Â These fundamental needs still exist and the health of the small number of individuals with life threatening illnessess in our nation should not be subject to Â cost effectiveness when our government is spending billions of pounds killing thousands of healthy individuals across the world and rescuing large greedy finacial institutions. With regard to costs, surely the manufacturers expensive research is already complete and while a small number of patients require this expensive treatment, compensation can be gained by the use of other drugs used by larger numbers of patients. Â Think basic economics - the laws of supply and demand
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the		

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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the		

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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients. For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should		

	not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, & we urge that any new reforms that come out of the consultation will apply to Revlimid
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, meaning that patients can remain on it longer. Revlimid is a convenient treatment for patient/families. Oral dosing does not involve the resource and time-intensive visits to hospital? patients can self-medicate at home/ work NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer. Revlimid offers therapeutic options to patients to get back into remission, improving their overall survival/helping to increase an independent life The Government now say that patients can pay for treatments if the NHS does not provide them. Revlimid costs Â£4368 pm Aricept (early stage Alzheimer?s) costs Â£75 pm. Both are currently rejected by NICE. It is clear that where treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden vs. treatment costing thousands every month, will be affordable to very few. Â If it remains rejected by NICE the financial burden on suitable candidates for Revlimid would be unmanageable.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (M). Â To Â reject it purely on cost alone is wholly inappropriate - solutions can be found to reduce its cost. Â Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of the patients.		

	For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. Â The recently announced NICE consultation on appraising higher cost treatments for rare diseases is extremely welcome and we urge that any new reforms that come out of the consultation will apply to Revlimid.
Section 2 (the technology)	Revlimid is the fist M treatment to be developed where the balance between clinical effectiveness and side-effects is excellent so much so that patients can remain on it longer term. Revlimid is convenient treatment for patients/families. Â Oral dosing does not involve visits to hospital - patients can self medicate at home/work. NHS access to Revlimid would ensure that M patients have treatment options even when they are refactory to other therapies and will help them live longer to benefit from future developments. R offers therapeutic options to patients to get back into remission, improving their overall survival and helping them lead an independent life. The Government say that patients can pay for treatments themselves if the NHS does not provide them. Â R costs Â£4368 monthly Aricept is Â£75 p m. Â Both are rejected by NICE. Â It is clear that where a treatment costs a few pounds a day, topping up is unlikely to prove a Â financial burden vs treatment costing thousands Â£ per month and will be affordable to very few. Â If it remains rejected by Nice the financial burden on the vast majority of M patients who are suitable candidates for R would be unmanageable.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	I have friends and relatives with Multiple Myeloma		
Comments on individual sections of the ACD:			
Section 1	Revlimid is a clinically effective treatment with impressive data		

(Appraisal Committee's preliminary recommendations)	supporting its use in myeloma. Rejecting it purely on cost is unacceptable. Â At this stage NICE, Government and manufactuers have a moral imperative for the best interests of patients to work together to reduce costs to levels acceptable to the NHS. Should NICE fail to reconsider its draft it will be increasingly difficult for patients to access this important advance in the treatment of myeloma. It will be a cruel burden if patients know there is a licensed, clinically effective treatment available which they cannot access. The experience of those I know who suffer from myeloma shows there is currently no formal way of dealing with it in the UK. I hope that the recently announced (and welcome) NICE consultation on appraising higher cost treatments for rarer diseases will quicky provide new reforms that will apply to Revlimid.
Section 2 (the technology)	Revlimid is the first myeloma treatment where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term. Revlimid is a convenient treatment for patients and the NHS. Patients can self-medicate at home or at work and the resource-intensive hospital visits for intravenous treatments are not required. NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments. Such options improve patients survival rates and help them lead increasingly independent lives. The Government now says that patients can pay out of their own pockets for treatments the NHS does not provide. Where the treatment costs thousands of pounds every month the top-up cost will be affordable to very few people. If NICE rejects Revlimid, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid will be unmanageable.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	sister of a multiple myeloma sufferer		
Location	Wales	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. NICE should not reject it purely because of the costs. There must be ways in which to reduce its costs. This is such an important breakthrough and and such an		

	important lifeline to myeloma sufferers that I would like to beg NICE the Government and the Manufacturers to try and find ways in which the price can be reduced and the drug made readily available. How cruel to know that your life could be saved if only the above mentioned bodies would get together and discuss the alternatives. NICE recently announced that that it would appraise higher cost treatments for rarer diseases, so please make that apply to Revlimid in a positive manner.
Section 2 (the technology)	Revlimid is the first myeloma treatment that is both effective and has limited side effects, thus enabling the sufferer to remain on the drug for a longer term. The fact that it is taken orally and can be taken at home or at work, makes it much easier for the patient and his/her family to cope with. Also it means that costly hospital treatments are not necessary. Bearing in mind how expensive hospital treatments are, this Â surely Â must have a bearing on the overall cost of Revlimid ? Â If Revlimid increases their life expectancy then the patients options will be greater and they Â will have access to other drugs developed in the future. Hopefully in the future drug manufacturers and Governments will be able to find ways of reducing the cost of new treatments. Lastly the Government is now allowing patients to pay for treatments themselves, or to top up the cost. The cost of Revlimid at a cost of Â£4368 per month would make it almost impossible for the majority of patients to fund. The answer must surely be to negotiate to reduce the cost of the drug, presumably the manufacturers would prefer to sell more of it?
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

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)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate - solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients. For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the		

	treatment of myeloma. The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid.
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term. Revlimid is a convenient treatment for patients and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments - patiehts can self-medicate at home or at work. NHS access to Revlimid would insure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments. Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an incresingly independent life. The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month. The top-up cost will be affordable to very few people, the financial burden for most patients would be unmanageable.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly		

	difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	i have seen the devastating side effects of the very expensive approved drugs used at present on one of my friends and I feel that no human being should be subjected to this treatment when there is a possibility to use one less damaging		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient Â For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma		

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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden. However, where the treatment in question costs thousands of pounds every month, such as Revlimid, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Relative		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced		

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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Relative of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1	Revlimid is a clinically effective treatment with impressive data		

(Appraisal Committee's preliminary recommendations)	supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient Â For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma Â The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]
Role	other

Other role	Relative		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient Â For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma Â The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid		
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Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			

Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role			
Location	Wales	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient Â For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma Â The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid		
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
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(manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
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Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			

Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid		
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Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes	My sister has multiple myeloma, and would probably benefit from treatment with lenalidomide. However,she is unlikely to receive this product due to the fact that she resides in Oxfordshire. Without it she may have just a few months to live.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid		
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Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5 (implementation)			
Section 6 (related NICE guidance)			
Section 7 (proposed date of review of guidance)			

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes			
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Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	friend		
Location	England	**Conflict**	no
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Other role			
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Role	Public		
Other role			
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Name	[redacted]		
Role	Local government professional		
Other role			
Location	England	**Conflict**	no
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Role	Public		
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Location	England	**Conflict**	no
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Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments ? patients can self-medicate at home or at work NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month Aricept (to treat early stage Alzheimer?s) costs Â£75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden. However, where the treatment in question costs thousands of pounds every month, such as Revlimid, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients		

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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Family member of Myeloma Patient		
Location	England	**Conflict**	no
Notes	No		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is		

recommendations)	wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients. For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma. The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid.
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Carer		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1	Revlimid is a clinically effective treatment with impressive data		

(Appraisal Committee's preliminary recommendations)	supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate- solutions can be found to reduce costs. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of the patient. Myeloma is such a terrible illness, please reconsider.To know that there is a licensed, clinically effective treatment which patients cannot have is dreadful. Any failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this very very important advance in the treatment of myeloma.The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcomeand we urge that any new reforms that come out of the consultation will apply to Revlimid
Section 2 (the technology)	Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side effects is excellent, so much so that patients can remain on it longer term. Revlimid is a convenient treatment for patients and their families. oral dosing does not involve resource and time intensive visits to hospital that is required for the administration of intravenous treatments- patients can self medicate at home or work. NHS access to Revlimid would ensure myeloma patients have treatment options even when they refactory to other therapies and will help them live longer to benefit from future developments. Newer treatments such as Revlimid can provide substantial benefit to patients in increasing the number of therepeutic options they have available to get back in to remission, improving their overall survival and helping them lead an increasingly independent life. The Government now say patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs Â£4368 per month.If Revlimid remains rejected, the financial burden on myeloma patients would be unmanageable.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (?M?). To reject it purely on cost alone is wholly inappropriate, solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced		

	which is acceptable to the NHS and in the best interests of patients. For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear . A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, & we urge that any new reforms that come out of the consultation will apply to Revlimid.
Section 2 (the technology)	Revlimid is the first treatment developed where the balance between clinical effectiveness and side-effects is excellent, so that patients can remain on it longer. Revlimid is convenient treatment for patient/families. Oral dosing doesnt involve the resource and time-intensive visits to hospital? patients can self-medicate at home/ work. NHS access to Revlimid would ensure patients have treatment options even when they are refractory to other therapies/help them live longer. Revlimid offers options to patients to get back into remission, improving overall survival and helping lead an increasingly independent life. Government say that patients can pay for treatments personally if NHS does not provide them. Revlimid costs ?4368 pm Aricept (treating early Alzheimer?s) costs ?75 pm. Both urrently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, ?topping up? is unlikely to prove a serious financial burden vs. treatment costing thousands of pounds every month, will be affordable to very few. If rejected by NICE, the financial burden on vast majority of patients who are suitable candidates would be unmanageabe.
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1	* Â Revlimid is a clinically effective treatment with impressive data		

(Appraisal Committee's preliminary recommendations)	supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient Â Â Â Â Â * For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â Â Â Â Â * A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma Â Â Â Â Â * The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
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Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6	

(related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Patient		
Other role			
Location	England	**Conflict**	no
Notes	I have been treated with Revlimid plus strong dexamethazone from July 2007 to January 2008 followed by a stem cell bone marrow transplant in April 2008. I returned home after my operation in Kings College Hospital in May 2008 and have been recovering since. Clinically I have had a good response from the treatment.		
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	* Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate - solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of the patient.* For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear. *A failure by NICE to reconsider its draft will make it increasingly difficult for patients to obtain access to this important advance in th treatment of myeloma.* The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK.The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid.		
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Section 3 (manufacturer's submission)			
Section 4 (consideration of the evidence)			
Section 5			

(implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
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Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	Public		
Other role			
Location	England	**Conflict**	no
Notes	* Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients Â Â * For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear Â Â * A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma Â Â * The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid		
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	higher cost treatments for rarer diseases is extremely welcome, and we urge that any new reforms that come out of the consultation will apply to Revlimid
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Section 7 (proposed date of review of guidance)	

Name	[redacted]		
Role	other		
Other role	Friend of patient		
Location	England	**Conflict**	no
Notes			
Comments on individual sections of the ACD:			
Section 1 (Appraisal Committee's preliminary recommendations)	? Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma. To reject it purely on cost alone is wholly inappropriate ? solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the myeloma community implore NICE, the Government and the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patient ? For patients to know that there is a licensed, clinically		

	effective treatment out there but that they cannot have it is a cross they should not have to bear ? A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of myeloma ? The rarity and severity of myeloma brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is to be commended, and I would urge that any new reforms that come out of the consultation will apply to Revlimid
Section 2 (the technology)	? Â Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so that patients can remain on it longer term ? Â Revlimid is ideal for the patient and their families. Oral dosing does not involve the resource and time-intensive hospital visits required for intravenous treatments ? patients can self-medicate ? Â NHS access to Revlimid would enable patients to have options that will help them live longer to benefit from future developments ? Â Treatments such as Revlimid can provide substantial benefits in increasing the number of options to get back into remission, improving their survival and helping them lead an increasingly independent life ? Â Patients can now pay for themselves if not provided by the NHS. Revlimid costs Â£4368 per month Aricept (treating Alzheimer?s) costs Â£75 per month. Both rejected by NICE. Where treatments costs only a few pounds a day, ?topping up? is unlikely to be a financial burden. However, where the treatment costs thousands of pounds monthly, the top-up cost will be affordable to very few people. If it remains rejected by NICE, the financial burden would be unmanageable
Section 3 (manufacturer's submission)	
Section 4 (consideration of the evidence)	
Section 5 (implementation)	
Section 6 (related NICE guidance)	
Section 7 (proposed date of review of guidance)	