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

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)	I am disappointed about NICEs decision that Ipilimumab will not be accessible by patients with advanced melanoma in the UK. The decision will be a hammer-blow to melanoma patients, their families and their carers. As you are aware from the evidence submitted, there are very few treatment options available to the patients with advanced melanoma. The recommended chemotherapy is old and not very effective. Ipilimumab has been a step change in treatment and shown in clinical trials to be of potential benefit to patients. I urge NICE to overturn its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 10:48:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I was very disappointed by NICEs decision that access to Ipilimumab will be denied to patients with advanced melanoma. The decision will be a massive blow to the hopes of the many patients, such as myself, who have advanced melanoma. The treatment options available to these patients are severely limited. Beyond old and largely ineffective chemotherapy regimens, the options are restricted to experimental treatments

	accessed through clinical trials. It is therefore massively disappointing that an innovative treatment, which has shown positive results through such trials will not be available to UK patients. I have participated in three clinical trials, after my disease progressed on the standard treatment of care. In entering these trials, I am very aware that there will not necessarily be a direct advantage to myself. Even if the proposed drug proves to be successful, then the benefit may be some years away and too late for me personally, it is of comfort that I may be benefitting future generations of melanoma patients. It is heart-breaking to think that such a sacrifice from previous patients will be wasted for UK patients, despite the efficacy of the drug.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	I urge NICE to review and overturn its decision.
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 10:40:00 PM

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)	It may be beneficial to administer Ipipimumab at an early stage while the tumour burden is low. It can take a few months before it starts working and it could therefore be beneficial to give Ipilimumab as a first line treatment.
Section 2 (The technology)	The success of Yervoy was mainly due to the 10mg/kg during the various trials AND the administration of re-inductions. Even the trial on which the approval was sought by BMS had re-inductions but were not approved by the EU. Immunotherapy is the only way still of achieving long overal survival rate of many years and it could work for patients regardless of their BRAF status.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	There is no mention of re-inductions and the fact that the 10mg/kg + re-inductions showed a long time survival rate of 10% higher than that for 3mg/kg + re-inductions. Predictive biomarkers are a double-edged sword unless they are highly accurate. From an economic point of view however, they are highly desirable especially for a drug at that cost. Assuming a high accuracy, they would avoid a patient wasting time on a treatment that will most likely not work. On the other hand, as there is nothing else available, people (myself included) will try, just in case, taking the side effects that may go with it. DTIC isnt exactly a walk in the park either, and it has very little response rates and little improvement in overall survival time.
Section 5 (Implementation)	www.nice.org.uk/guidance/TAXXX is not a valid URL. NICE would be in a prime position to re-negotiate a price with BMS.
Section 6 (Proposed recommendations for further research)	Prevention is a good thing, but too late for those who have been diagnosed as stage 4. Just like the effects of smoking were not known a few decades ago, the effects of sunburns and sun exposure were not as well published as now. Melanoma can take many many years to develop until it is detected. A fair bit of people diagnosed now in my age range (35-45 and above) are victims of the lack of public information at the time. Sun exposure is also not the only way to develop malignant melanoma. It is a common theme on forums that people were told by GPs

	that moles were nothing to worry about which then later turned out into stage 3/4 melanoma. Referring too little can in effect increase the cost of overall melanoma treatment.
Section 7 (Related NICE guidance)	With the only approved drug being DTIC, my life expectancy doesnt reach as far as 2015. With a drug like Yervoy there may at least be a small chance of surviving until then.
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 9:20:00 PM

Name	[redacted]
Role	other
Other role	Associate professor and Consultant, Karolinska Institutet, Stockholm, Sweden
Location	Other
Conflict	yes
Notes	Investigator and Swedisch PI in MO25515 trial of ipilimumab
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	There should not be a general negative recommendation since obviously there is a need for improved therapy in this situation, and clearly a subgroup benefits from this drug. Predictive tests are obviously needed and a moratorium on use of drug will not enhance this. A restricted use to specialist centers and registering of clinical data and collection of biomarker samples (tumor, Plasma, normal DNA etc) should be mandatory or strongly recommended both to BMS and the participating centers
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	I do not follow the argument that despite evidence that this therapy meets an unmet need and provides extension of survival it still is not recommended, apparently for economic reasons. This seems to be a very hazardous decision, since the evidence for benefit are significant and robust, whereas the health economics evaluation rests on uncertain assumptions and is therefore not reliable.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 8:20:00 PM

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

Name	[redacted]
Role	Patient
Other role	
Location	Other
Conflict	no
Notes	Anay medication that help and increase patient life should be avealable to any of them
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 8:05:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	Europe
Conflict	no
Notes	[redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The decision to propose ipi should be left in the hands of the physician/oncologist after discussion with his patient, taking into account particular circumstances that are known by them only, to define the therapeutic strategy most appropriate for this singular patient. The median strategy is not relevant for everyone.
Section 2 (The technology)	2.1: Ipi has received Mktg authorization in uk for adv. Melanoma in people who received prior therapy (in 2.1 above) but... Is not recommended for the same indication (1.1)???? Dont understand. 2.3: studies show that 10mg/kg may be better. Cfr http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(09)70334-1/abstract

	Cost Will lead many Health Technology Assessment or similar bodies to conclude that it is not "worth" paying for ipi. The Voice of patients is never listened to in this discussion because they are not represented.
Section 3 (The manufacturer's submission)	How was the economic valuation modelized and faced with real Life? Eg does it take into account that higher QOL helps you to keep your job, lowers use of social services because you Play your role in society as a parent, not default on your mortgage loan,... I wonder if s f36 and eortc qlq-c30 questionnaire adequately captures this. do they know that on avg, cancer patients pend 123 ?/ month in Complementary and Alternative Medicine (http:// annonc.oxfordjournals.org/content/16/4/655.long)? 3.17 is cary: ERG considÃ¨rs benefits of ipi substantially overestimated!
Section 4 (Consideration of the evidence)	if only they had a biomarker! I believe that, at least for those who experience long- term benefits of ipi, the magnitude of the benefits is understated.
Section 5 (Implementation)	involvment of patients representative in this process? Nothing about us without us!
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 7:12:00 PM

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

Name	[redacted]
Role	Patient
Other role	Retired General Practitioner
Location	England
Conflict	yes
Notes	I Recieved ipilimumab in Sept 2010 stage IV Ocular melanoma - I am alive and well today over a year later.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The whole process is discrimiatory to people like myself with disablity (cancer) as it has not defined the different groups of melanoma well enough. It compared ipilimumab to current treatment of benefit- this is only o f benefit to some groups of melanoma. It takes no account of the fact that the nation can afford health care for things that are of personal choice ie c section obesity surgery - Us with cancer have no choice there is no effective drug for ocular melanoma - none of proven benefit other than ipilimumab
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 5:01:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a stage one melanoma patient already living in dread of either a reoccurrence or a new primary. I am 42 years old and my three children need me. I would like the opportunity to extend my life for their sake should that happen. I feel it is immoral to deny this long awaited treatment should the worse happen to me and to those already living with advanced melanoma!
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 4:57:00 PM

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

Name	[redacted]
Role	Carer
Other role	MD/PhD working as fundamental researcher outside cancer research
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Advances in Stage IV Melanoma treatment have been impressive over the last years they now make long-term survival if not cure a possibility of the nearer future, something that was just unthinkable as little as 5 years ago. The lack of effective current therapy options and NICEs decision to not recommend Ipilimumab denies UK stage IV Melanoma patients to be part of that future. Ipilimumab is a novel drug, first dosing schemes are therefore unlikely to be the optimal ones. I had expected NICE to use their negotiation power to ensure research into a better dosing scheme is undertaken (along the lines of the FDA decision) while ensuring access to the drug for UK patients by e.g. granting a preliminary recommendation at a lower price. Leaving patients with a goldstandard of therapy with a response rate below 20% can hardly be considered a state-of-the-art cancer therapy of the 21st century in a country of the first world.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	I am surprised to see that Ipilimumab is considered entirely out of context of the recent development in Melanoma therapy where the combination of conventional, immuno- and targeted therapy promises for the first time a long-term perspective for stage IV Melanoma patients. Cancer, especially in advanced stages, has been shown to be too complex to be treated by a single agent, so patients will need access to all components to get a chance for long-term survival. While the current scheme of Yervoy definitely requires further research (results with e.g. the 10 mg dosing scheme show more promising results) the current scheme gives patients at least a chance to still be alive when better therapies become available.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE	With the current median survival for Melanoma, 2015 means that the majority of the current stage IV Melanoma patients will

guidance)	no longer be alive at the time-point of this review. An early review date would reflect the fact that the current chemotherapy golds
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 4:10:00 PM

Name	[redacted]
Role	Patient
Other role	FDA patient advocate, retired professor of biological anthropology
Location	US
Conflict	no
Notes	I am a 71 year old man with stage 4 melanoma. I had four ipilimumab infusions (3 mg/kg) in April-June of 2010 in the Expanded Use setting. All my tumors (over a dozen) either shrank or disappeared within 20 weeks, and the remainder have remained quiescent in the intervening 16 months, and my health is very good. Since my treatment, I have become a patient advocate for the FDA and for a melanoma support organization (the Melanoma International Foundation).
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If Bristol-Myers Squibb were charging substantially less, there would be no question that this drug should be approved by NICE. It represents a significant advance in melanoma treatment, and the immunomodulatory approach is going to replace many of the very poor and ineffective current treatments (dacarbazine, interleukin-2, alpha-interferon, among others). Some of these are actually themselves extremely costly and are very negative in terms of quality of life effects. I strongly urge NICE to find a way to negotiate the cost of ipilimumab down to a reasonable level. I would remind NICE that other, potentially even more effective immunomodulatory drugs (particularly anti-PD1 and anti-PDL-1) are in development for melanoma as well as other cancers and these will likely be priced in similar fashion as ipilimumab. The combination or serial use of these drugs may well be extremely effective, so that negotiating their costs down will be imperative.
Section 2 (The technology)	As noted in the SPC, the side-effects are very well managed in almost all instances. I had watery diarrhea twice during my treatment, but a course of low dosage steroids (metropak tapering over 5 days) immediately took care of it. I also was tired for 2 weeks while my immune system was responding (weeks 10-12) - I needed to rest after walking 2 miles. These sorts of side-effects are minimal by comparison with those from alpha interferon or Interleukin-2 (I did both and dropped interferon after 6 dreadful weeks being half-dead, and almost going into a coma and having atrial fibrillations with IL-2). There were 2 early deaths reported with ipilimumab (colitis), but these were because of unfamiliarity with the symptomology and unusual side effects. These are NOT an issue with well-trained

	physicians and compliant patients.
Section 3 (The manufacturer's submission)	As noted, these model extrapolations are always open to question. The long term benefits of ipilimumab and developing immunomodulatory drugs are only going to be well established over the course of 5 years (or more) of follow-up. My guess is they will be significant from what I know of anecdotal accounts of patients 10 years out.
Section 4 (Consideration of the evidence)	This is a far too narrow consideration of the evidence. As with the US FDA, evidence beyond the narrow phase III clinical trial should be considered. This led the US FDA to approve ipilimumab as a FIRST LINE systemic treatment for melanoma, not simply as an end-of-life enhancer for 400 advanced patients. This is a major error. Also, it is becoming clear in trials that some other solid tumor cancers are likely well treated with immunomodulatory drugs such as ipilimumab, so its application can not be so summarily minimized.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 3:43:00 PM

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

Name	[redacted]
Role	other
Other role	[redacted]
Location	Europe
Conflict	yes
Notes	European Cancer Patient Coalition which supports M-ICAB receives funding. All details are reported here: http://www.ecpc-online.org/about-ecpc/finances/sustaining-partners.html
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	For patients in EU ipilimumab mets the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration is robust. So we do not really support the preliminary recommendations. Personally I am 41, have two young kids and are a stage IV patient since Nov 2009, if it was not for ipilimumab I would probably not be here today. I have worked and contributed to society a 100% all through my illness.
Section 2 (The technology)	Point 2.2 - I had only mild side effects and enjoyed full quality of life during treatment. Most patients I have met report similar experiences. With close follow up side effects are totally manageable and minimally interfering with quality of life. Point 2.3 - Patients agree that the price currently asked by BMS is not sustainable and is something that needs to be negotiated down
Section 3 (The manufacturer's submission)	3.10 Health-related quality of life used by industry fail to represent what ipilimumab really means for metastatic patients who have at least some hope of having "DURABLE" responses with amazing quality of life. A EU wide study should also include the perspective of all the patients who benefited from their EAP. 3.13. The benefit over and beyond DTIC has been demonstrated. At three years, overall survival was 20.8 percent for the combination compared to 12.2 percent for chemotherapy alone. (see ASCO 2011).
Section 4 (Consideration of the evidence)	Availability and nature of evidence - evidence of superiority compared to DTIC exists. Uncertainties around and plausibility of assumptions and inputs in the economic model- from the perspective of a patient the true magnitude of the survival benefit of 2 YEARS is already HUGE, it seems that BMS zest to infer a CURE without enough evidence has not served patients here. We need this, we will take those extra 2 years (especially in the perspective of allowing us to bridge to other therapies that are entering the market such as Zelboraf) and the possibility of the benefit that is achieved from re-induction of these drugs. Most likely cost-effectiveness estimate (given as an ICER)-

	Patients in EU feel the change in health-related quality of life had been inadequately captured in the economic analysis. More patient input into what it really means with regards of quality of our lives would substantially change this.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 3:35:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	Europe
Conflict	no
Notes	I am a Stage 4 patient who was able to obtain the drug via a clinical trial, and benefited from it. Although I was not full respondent, I am still benefiting from the drug, though it is already 9 months since the last infussion. No side effects, no problems, performance status 0 - no limitations.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The only approved therapies are all very toxic chemotherapies that have limited or no effect on PFS, and no effect on OS. Ipilimumab is the only EMA approved drug that provides both PFS and OS benefit to patients population. The benefit of ipilimuab can manifest even for patients who are not "deemed" to have response, via decreased tumor aggresiveness, lower volume of decease, and thus significantly improving the Quality of Life.
Section 2 (The technology)	The advantage of ipilimuab includes the fact that it is administered in 4 out-patient IVs, thus decreasing the associated costs of hospitalization, and at the same time, increasing the quality of life of patients as they do not need to spend the time in hospitals.
Section 3 (The manufacturer's submission)	The AEs of ipilimumab are now very well understood and can be easily managed in most cases, especially if the communication between the patient and the health practitioners are well established. In addition, many patients go through all 4 cycles without any or very mild side effects. The calculation could not take into effect the fact that for those patients who achieve positive response, the effect might be long lasting, several years. And with development of new drugs, it might mean that the patients might live long enough to take benefit of future treatments. As such, it might mean a vehicle how to get eventually cured.
Section 4	n.a.

(Consideration of the evidence)	
Section 5 (Implementation)	n.a.
Section 6 (Proposed recommendations for further research)	n.a.
Section 7 (Related NICE guidance)	n.a.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 1:53:00 PM

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

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)	I really dont understand how you are able to make such a recommendation! There is outstanding evidence of such impressive results which to date is something that melonoma sufferers have not previously experienced. My wife is currently stage 4 and during her illness we have become acquainted with many other sufferers and their families and to learn that you have not recommended Ipilimumab just feels so very unfair. Having both worked all our lives my wife & I see this as probably the only time we have needed something back in return and your actions have just removed the chance of that happening - Thanks!
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/4/2011 11:39:00 AM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Ipilimumab is the first drug to have made a difference and gives hope to people suffering from Melanoma. Familes are being devastated by the decision to withhold the drug. Please reconsider.
Section 2 (The technology)	Melanoma sufferers will gladly put up with the side effects if it means they have a chance of a longer life or in some cases a

	cure.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/4/2011 11:27:00 AM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which

	time this may be too late.
Section 8 (Proposed date of review of guidance)	
Date	11/3/2011 11:17:00 PM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am aware that there has been no treatment for melanoma until now. I find it deeply upsetting that a drug which can have a huge impact on the lives of sufferers is not being recommended on the basis of cost. I know a sufferer and find it shocking that this drug is available to others yet because of where he lives he and fellow sufferers are being discriminated against. I hope this situation will be rectified soon.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	I find it shocking that sufferers will have to wait for 4 years before this drug be made available to them. Surely it is unethical to withhold a treatment which has been found to have a significant effect and given my understanding is being used at the mo
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/3/2011 8:52:00 PM

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

Name	Mrs [redacted]
Role	NHS Professional
Other role	Friend of person with melanoma
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	A lt of people with thbis disease are quite young, with young families. They should recieve this drug to give them as much time as possible with their loved ones
Section 2 (The technology)	Dont believe a price should be put on peoples lives
Section 3 (The manufacturer's submission)	Perhaps should the manufacturers should think about reducing the price of these vital drugs, thus making it available to more people and thereby selling more of their product
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/3/2011 7:06:00 PM

Name	[redacted]
Role	NHS Professional
Other role	Patient
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	30% of patients treated with Ipilimumab weill experience an improvement in median survival time. This compares favourably to other treatments available for advanced malignant melanoma. There is little alternative available and as many people with the condition are of working age this would be a great loss financialy to society.
Section 2 (The technology)	Given the poor prognosis with advanced stage melanoma many patients would be willing to tolerate the side effects for a prolonged life, especially as most are younger people. The cost of administering the drug like most others will be high initially but likely to decrease with widespread use.
Section 3 (The manufacturer's submission)	The evidence shows that ipilimumab ofers a some survival gain, and more widespread use would allow for more detailed data to

	be collected. More widespread use would also provide information on those patients who would gain most benefit from the drug and therefore can be targeted more appropriately.
Section 4 (Consideration of the evidence)	Ipilimumab has been shown to be life extending and would only be required by a small group of people. There are no other alternative options available at the present time.
Section 5 (Implementation)	There is significant cost, but with this disease on the increase and the patients being mainly of a younger age it seems unethical not to provide such a treatment, especially when it is available in other parts of the country.
Section 6 (Proposed recommendations for further research)	The importance of sun protection cannot be underestimated, but there are still increasing numbers of people being diagnosed with melanoma and an effective treatment is needed.
Section 7 (Related NICE guidance)	Three years is still a long time to wait for this to be reconsidered and any advance or breakthrough in treating melanoma should be encouraged and tested.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/3/2011 2:36:00 PM

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

Name	[redacted]
Role	Public
Other role	husband of doctor in palliative care
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel that this drug must be provided for people with metastatic melanoma. I appreciate the cost implications but this a treatment that deserves to be prioritised. I agree with all of [redacted] comments (submitted to NICE). As a member of the general public I urge that his consultation process, and method of responding is made much easier.The current system must limit responses fron the public many of whom will not understand the guidance here. Can a plain english version (along lines of a patient information sheet) be provided.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/3/2011 12:39:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	I am a palliative medicine consultant who has cared for people with malignant melanoma at the end of their life.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I urge the comittee to review their guidance.Metastatic melanoma is a devastating illness with high symptom burden, limited treatment options and very poor prognosis. 30% of people treated with ipilimumab will experience an improvement

	in median survival, and 10% of people will have long-term benefits. This offers an opportunity to offer this group of patients, many of whom are young, a vital treatment option.
Section 2 (The technology)	This drug offers fewer side effects to chemotherapy for melanoma which is often toxic with poor response rates. I believe the route duration and side effects would be acceptable to patients and able to be administered within chemotherapy day areas. As there is not a risk of neutropenic sepsis admissions to acute hospitals and oncology units for should be less, saving cost in addition.
Section 3 (The manufacturer's submission)	This outlines good data on trials thus far conducted. Increased use allows further evaluation of this drug.
Section 4 (Consideration of the evidence)	This treatment is effective needed and only being discounted on grounds of costs the QALY and other analyses and not easy to interpret and will certainly confuse members of the public and thoise without specialist knowledge.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	I would urge that as it has been 30 years for any breakthrough in treatment of melanoma that this guidance is reviewed urgently. A great deal of funding has been allocated to new treatments for other types of cancer and I believe melanoma as a cancer has
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/3/2011 12:24:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	Dear NICE, I am writing as a member of the general public who supports the [redacted] and who has personally experienced the fright of malignant melanoma at the age of 18. As we all know cases of malignant melanoma are rising fast both in young and older people and the consequences are scary and horrific, and up until now there has been very little hope for people with advanced melanoma. It is with utmost happiness that I hear of a new drug that can pro-long the life of people with advanced melanoma. Often sufferers are told they have very little time left to live. Imagine, someone who has advanced melanoma knows there is a dug out there that could save them but cannot do anything about it because it is too expensive for them to afford? People who have never experienced the shock horror of being told they have a deadly cancer probably cannot imagine how important it is that this drug is available for people with advanced melanoma. If they have a chance of living then surely it would be a tragedy to deny this chance and hope. I ask what is the POINT of doing all this research if the results are going to be denied to so many people? I ask the people of NICE who have the authority to change this decision, to try and put themselves in the position of someone who has been told they have a few months left to live and realise that everyone should have the right to life.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed	

recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/3/2011 1:40:00 AM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As I understand, the drug ipilumumab is proven to keep malignant melonoma stable in most cases. As a friend of a sufferer of this disease, I find it disgraceful that this treatment is withheld in Scotland on a matter of cost when it is available in many areas of England. I would like this situation to be reassessed immediately.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	I am disappointed that guidance for this new treatment will not be reviewed for another 4 years. Ipilumumab is the biggest breakthrough in melanoma treatment for 30 years and I believe that for such an important life prolonging treatment, the guidance f
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/2/2011 10:34:00 PM

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

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 a 62 year old [redacted] with metastatic melanoma. Just now I am well.I play [redacted] play with my grandchildren and am still working. I have a wonderful life and the thought of my illness worsening is truly terrifying for myself and my family.. Without ipilumimub there is no hope.There is no possibility of growing old and watching my grandchildren grow up. If the case for ipilumimub was futile I wouldnt ask but the statistics are solid. [redacted]my [redacted]children work in the nhs and I know what a wonderful job it does. I have always been a strong proponent of the nhs. Anything I can personally do to help myself I will do- as I have always done. Sometimes in life you cannot be to proud to ask for help. This is that time for me. Please allow patients like myself with advanced melanoma the possibility of a life and future. A good doctor will try to treat their patients as they would a family member.Please consider this carefully. Accept ipilumimub on the nhs and allow this small group of patients a fighting chance.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	2015 is a long way off for patients with advanced melanoma. It should be reviewed much in advance of this
Section 8 (Proposed date of review of guidance)	
Date	11/2/2011 8:44:00 PM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no

Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	wish to voice my disbelief at the recent decision by the National Institute for Clinical Health and Excellence (NICE) to deny access to the drug Ipilimumab for sufferers of advanced melanoma. My friend has metastatic melanoma. A true gentlemen and family man. Finding out that he had cancer was heartbreaking for his friends and family.It is even more heartbreaking to know that there is a drug which may help but it is impossible for him to access. This is a horrible aggressive disease. This drug is valuable even from a palliative point of view. Use of this drug will allow it to be developed to ultimately find a cure. Melanoma treatment has been at a standstill for 30 years. This is a coldhearted decision which would stunt the development of this drug for how long? another 30 years? I wholeheartedly believe this treatment should be available throughout the UK with immediate effect. Please ensure that there is access to this drug as soon as possible
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	THis is a ridiculous timescale.This drug should be a springboard for finding a cure for melanoma. At this rate it will be another 30 years before we are any further forward
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/2/2011 5:32:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My father in law is [redacted] and has Melanoma. Having researched this type of cancer online there appears to be very little effective treatments available in Scotland. I believe the new drug ipilumimub has been proven to keep the disease stable in a very substantial proportion of people and cure in a small number. I find it extremely upsetting that he currently has no hope of getting treatment despite it being used in areas of England, Europe and America. I wish to express my extreme disappointment in this and hope that this will be reassessed immediately.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	Once the decision on ipilumimub has been made reassessment of the guidance is to be in 2015! This is an incredible timeframe to assess a rapidly changing situation in the treatment of melanoma. I believe it should be revisited in 2012 at the very latest
Section 8 (Proposed date of review of guidance)	
Date	11/2/2011 4:48:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Wales
Conflict	no
Notes	[redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The ACD in its recommendation appears to have given more weight to the cost of this treatment, equal weight does not appear to have been given to the clinical effectiveness of this

	drug, the only one of its kind in this group of patients, who have no proven alternative in this setting.
Section 2 (The technology)	This treatment is over priced. Does NICE have the powers to negotiate with the manufacturers to arrive at a more agreeable price? Would it have that power in its current form or in some other form in the reformed NHS?
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	I accept that with the available evidence, this treatment does not appear to be cost effective, though equal weight does not appear to have been given to the these factors: 1. this is the first ever drug to have shown an improvement in overall surival in this disese. There are no evidence based alternatives in the 2nd line setting. Unlike many solid cancers, where there are several options (3 or more valid and clinically proven options for treatment, eg breast and colorectal and lung cancers to name the most common), advanced melanoma patients have just one treatment approved more than 3 decades ago and without a strong clinical evidence for its efficacy. It can be argued that denying the only proven drug on the basis of cost alone, is unfair and discriminates against those with this particular condition. 2. The drug is innovative and is being considered for end of life use, with the potential to achieve long term remission in a small subset of patients. 3. Melanoma has one of the fastest increasing incidence rates among all solid cancers. The number of patients being denied this treatment as a result of this recommendation is bound to increase in future years.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	DR[redacted]
Date	11/2/2011 12:25:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I disagree with the provisional Appraisal Consultation Documentation.
Section 2 (The technology)	This drug is hte first drug licensed since the 1970s for the treatment for advanced melanoma and NICE have themselves acknowledged that this is a steep change in the treatment for advanced melanoma
Section 3 (The manufacturer's submission)	This drug addresses an unmet need. There will be a huge impact on patients if this drug is rejected by NICE. For example this is the only therapy that has been shown to increase the 1 year survival rate compared to its comparator in a Phase 3 clinical trial.
Section 4 (Consideration of the evidence)	The incidence of melanoma is increasing. Over the last 25 years the rate of malignant melanoma has risen in the UK faster than any other of the top 10 cancers in the UK. It is the second most common cancer in the 15 - 34 age group. More than 11,700 people in the UK are diagnosed with malignant melanoma each year. They need this lifeline.
Section 5 (Implementation)	We watched helplessly whilst our dear friend and colleague battled malignant melanoma - losing her fight just over six months after diagnosis. This treatment is vital for such a vulnerable group of people
Section 6 (Proposed recommendations for further research)	Personal viewpoint - to NICE, Ipilimumab is not cost effective. How much is an additional year of life worth? In order to beat this cancer it is vital that sufferers are given hope and additional time with their families and friends.
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/2/2011 12:09:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	As a stage 4 patient who may be needing access to Yervoy in the near future I am disappointed to hear of NICE's decision to

recommendations)	deny access to Yervoy to people with advanced melanoma.As a [redacted]year old with 3 small children I am not ready to give up on my life and thanks to Yervoy surviving is something that I can aim for. NICE assessment focuses on patients that have a visible response on the disease and seems to ignore all those who achieve stable disease.I would be very happy with SD since I am currently asymptomatic however I know that without Yervoy I will eventually become symptomatic thus stopping me from being a providing father and husband.I am not unique in this. This is important because of the new promising drugs in the pipeline and moreover combination of drugs will yield even better response rates so buying time here is not in the traditional sense but may well make the difference between life and death. I am currently on Vemurafenib EAP, if I manage to keep my burden low,when the time comes for me to go on Yervoy,and if I am one of the long term respondents,I should have 40+ years of good quality life in front of me.Allowing me to see my children grow and be there for them
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	Today Ipilimumab offers the best chance of a "cure" for Stage 4 melanoma patients. Judge the drug not just on the median improved OS but consider the impact on the tail - where 15-25% can be considered to be operationally cured. Stable disease is acceptable to a large number of stage 4 patients and may lead in time to better treatment options and ultimately to cronicisation (if not cure) of the disease.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/2/2011 9:56:00 AM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now and yet NICE has chosen to deny this treatment to sufferers and their families despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. This should be the gold standard in advanced melanoma treatment. I strongly disagree with the assessment. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced. By making this decision the effort and technology which has gone into this to date is wasted.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great. It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.

Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available immediately rather than within 3 months of the guidance being published
Section 6 (Proposed recommendations for further research)	Unable to access these guidances to comment.
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use i
Section 8 (Proposed date of review of guidance)	
Date	11/2/2011 9:50:00 AM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	What kind of world do we live in? How is it fair to take away a drug from someone that gives them the chance to live a longer life? These people are thinking of saving money not lives! how can this be right! you can not put a price on someones life.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/1/2011 10:44:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	US
Conflict	no
Notes	I was very disappointed to hear about NICE's decision to deny the drug 'Yervoy' for individuals with advanced melanoma. A shocking decision that will affect the life expectancy of many with advanced melanoma. I hope that this preliminary decision will be overturned because please dont condemn a young mother of three small children, when you could possibly give her life. We beg you to reconsider.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/1/2011 8:09:00 PM

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 VERY disappointed to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because my dad has melanoma and i still very much need my dad. I need him here to hug,

	advise me through the hard times, be proud of all i achieve and when i go off track guide me back. My dad is a credit to our society and if he were to be taken before his time then the world would be a less nicer place. He has fought for our country, does so much for his friends and family, he is our rock. Patient's hopes have been dashed. It is devastating that many patients have been left with little hope.I urge NICE to review its decision to give people like my dad a better fighting chance. Every moment counts so dont deny us of this!!!
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	11/1/2011 7:37:00 PM

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

Name	[redacted]
Role	other
Other role	Friend of patient
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	A friend of mine is presently suffering from metastatic melanoma I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now and yet NICE has chosen to deny this treatment to sufferers and their families despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. This should be the gold standard in advanced melanoma treatment. I strongly disagree with the assessment. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced. By making this decision the effort and technology which has gone into this to date is wasted.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great. It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available

	immediately rather than within 3 months of the guidance being published
Section 6 (Proposed recommendations for further research)	Unable to access these guidances to comment
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use i
Section 8 (Proposed date of review of guidance)	
Date	11/1/2011 6:55:00 PM

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 very disappointed to hear of NICE's decision that this new drug ? Yervoy for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to you because a close friend is suffering and needs this drug. I strongly urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	Liz Henstridge
Date	11/1/2011 1:46:00 PM

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

Name	[redacted]
Role	[redacted]
Other role	
Location	England
Conflict	no
Notes	Im am disappointed to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. One of my oldest friends and ex-Army buddies is actually going to die unless he can get this drug. He is only 50 and would leave behind a wife and two young children. This is an outrage when it might be possible to avoid by spending a bit more money! Patient's hopes have been dashed. It is devastating that many patients have been left with little hope and I urge NICE to review its decision.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	Yes, the treatment is relatively expensive but how much exactly is a human life worth? Compared to the amount our government spend spent saving lives in other countries, this cost is nothing!
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	11/1/2011 5:58:00 AM

Name	[redacted]
Role	Public
Other role	Good friend
Location	England

Conflict	no
Notes	How on earth can you allow people to suffer and die because of money? you should be ashamed.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am disappointed to hear of NICE's decision that this new drug 'Yervoy' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because I have lost many friends from my army days to melanoma, also my father suffered with melanoma although did not die from it. In this day and age it is criminal to deny people a viable treatment that could save a life due to its cost. Perhaps we should sack all consultants in hospitals as they are expensive, or maybe forget about brain surgery as this too is expensive. The point is, melanoma is a killer, there is a viable treatment and cost should not be a factor in denying this treatment. Patient's hopes have been dashed. It is devastating that many patients have been left with little hope. I strongly urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/31/2011 9:53:00 PM

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

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 compelled to comment given the disturbing action to deny the availability of a life-saving drug, for perceived FINANCIAL unfeasibility. This basic lack of humanity has angered thousands whether or not they are affected by advanced melanoma. The idea that financial well-being comes before human well-being is self-defeating, unsustainable and inhuman. As Im sure will become obvious by the vehement objections, this action needs to be overturned. People will lose lives at the hands of this decision, and citizens will be disillusioned as to the benefit of our considerable medical advancements if we are to reject their practical application in favour of financial comfort. Like most on this planet, I would consider the human cost to be a more expensive one. I urge NICE overturn this decision, and stand for a societal climate where people, not money, come first.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 9:05:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	I am disappointed to hear of NICE's decision that this new drug 'Yervoy' for people with advanced melanoma has been denied.

recommendations)	This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is very important to me because I have a close friend, whom I have known for over 35 years who is suffering with this condition. Many patient's hopes have been dashed. It is devastating that many patients have been left with little hope. I urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/31/2011 8:27:00 PM

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

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 find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 6:50:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Other
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 6:44:00 PM

Name	[redacted]
Role	Public
Other role	
Location	Other
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for

	the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/31/2011 6:42:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Other
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 6:40:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	I am shocked and very much appauled at NICEs decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This drug could help so many is a literally killer blow to people for people with advance melanoma and those who care, know and love them. I feel so strongly about this as i have someone very close to me

	being affected by this devastating blow. [redacted] is a Melanoma victim and has been my [redacted] and friend for 8 years. He has always been the best he can be for everyone else in life and always put others ahead of himself. He is a Husband to a beautiful wife and a father of 2 wonderful children. With this drug he has the chance to prolong his life and give myself and others the chance to give back to him and show him the appreciation he deserves. I will be writing to my local MP in a hope that he will show his support for people in need. I dont understand what gives anyone the right to put a price and decide against a drug that can help so many people get extra from life. Just imagine someone you know was affected by this and wasnt given every possible option because of cost, how would you feel. Thank you for spending the time to read this and please take it into account and make this drug available to people who really need it.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	am shocked and very much appauled at NICEs decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This drug could help so many is a literally killer blow to people for people with advance melanoma and those who care, know and love them. I feel so strongly about this as i have someone very close to me being affected by this devastating blow. [redacted] is a Melanoma victim and has been my [redacted]r and friend for 8 years. He has always been the best he can be for everyone else in life and always put others ahead of himself. He is a Husband to a beautiful wife and a father of 2 wonderful children. With this drug he has the chance to prolong his life and give myself and others the chance to give back to him and show him the appreciation he deserves. I will be writing to my local MP in a hope that he will show his support for people in need. I dont understand what gives anyone the right to put a price and decide against a drug that can help so many people get extra from life. Just imagine someone you know was affected by this and wasnt given every possible option because of cost, how would you feel. Thank you for spending the time to read this and please take it into account and make this drug available to people who really need it.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	

Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/31/2011 5:49:00 PM

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

Name	[redacted]
Role	Public
Other role	Parish Councillor
Location	England
Conflict	no
Notes	My Mother died for need of a treatment which worked in this way and after becoming a human guinea pig to trial drugs which might help others after her passing. Now my niece has been let down by her Doctors surgery (on two occasions) and by then by her hospital. This has resulted in a melanoma being missed until out of control! Yervoy could be a lifeline for her and you have decided not to licence it! We have been crying out, for a drug to work with the immune system, for years PLEASE, PLEASE, PLEASE - PLEASE change your minds when you vote again!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Which other drug IS licenced which will has the same effect?
Section 2 (The technology)	The side effects are the same in many drugs which are simple and certainly do not have the ability to change lives - as this does.
Section 3 (The manufacturer's submission)	The manufacturers could be held to account if the drug does not perform as well as they claim and thus their claims should not preclude its use. This is long awaited breakthrough.
Section 4 (Consideration of the evidence)	You consider the trial evidence robust - if it were to help one young person extend their life - it should be licenced.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 4:59:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	I must state that I am disappointed to hear of the decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue

	to have limited treatment options beyond the standard of care. This issue is important to you because I have a close friend suffering and he has just made me aware of this whole situation. It is devastating that many patients have been left with little hope. I sincerely urge NICE to review its decision.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am very disappointed to hear of the decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. Quite frankly this is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because I have a close friend suffering and he has only just made me aware of this issue, and to be honest I find it incredible to believe this is even being contemplated. It is devastating that many patients have been left with little hope. I urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/31/2011 4:51:00 PM

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

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I understand that as yet there is no successful treatment for advanced malignant melanoma and until we have more information on how successful these new biologics are on the disease that it is unlikely that we can move forward. This drug has been shown to be successful in a small cohort of patients, maybe by extending the number of patients that have access to this drug we will find the reason why we have success with some patients and not others.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This drug offers the first real chance for patients with end stage malignant melanoma. This disease affects many young otherwise fit adults and denying them the chance of increased survival in order to fulfill their ambitions to see their families grow fo
Section 8 (Proposed date of review of guidance)	
Date	10/31/2011 9:11:00 AM

Name	[redacted]
Role	other
Other role	Parent [redacted] who died through melanoma
Location	England
Conflict	no
Notes	Actively involved in raising funds to be used in research into malignant melanoma
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Disagree with the findings of the appraisal committee.
Section 2 (The technology)	

Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	NICE themselves acknowledge this is a step change and the first new treatment in 30 years. The rise of Malignant Melanoma in young adults continues, faster than any other cancer. The committee acepts that ipilimumab is life extending. As the Father of a 24 year old, who went through 3 years of torment from first diagnosis to his final death through metatastic tumour on the brain, this could have been significant. To put a statement of cost effectiveness of life to a 24 year old is callous and should not be a consideration in our society. I would ask what options are NICE accepting if this is not made available.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/30/2011 8:43:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	A family friend is presently suffering from metastatic melanoma I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now and yet NICE has chosen to deny this treatment to sufferers and their families despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. This should be the gold standard in advanced melanoma treatment. I strongly disagree with the assessment. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced. By making this decision the effort and technology which has gone into this to date is wasted.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust.However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option.It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great.It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available

	immediately rather than within 3 months of the guidance being published
Section 6 (Proposed recommendations for further research)	Unable to access these guidances to comment.
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug.Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in so
Section 8 (Proposed date of review of guidance)	
Date	10/30/2011 6:27:00 PM

Name	[redacted]
Role	NHS Professional
Other role	General Public
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I was very disappointed to hear that Ipilimumab Is going to be denied to patients with advanced melanoma. This drug has a clear survival advantage in a disease with a bleak prognosis. This disease affects many young people with families to whom time is precious. The GMC states that our duty as a doctor is to prolong life and yet a drug which has been shown to do so is not able to be prescribed. This is clearly a devastating blow to patients and their families. A good friends father has recently been diagnosed with melanoma and I have seen at first hand how aggressive this disease. I am shocked that a treatment with clear survival benefits is not being offered.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/30/2011 6:23:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My son's father in-law is suffering from metastatic melanoma and I find the decision NICE has made regarding Ipilimumab unacceptable. There have been no effective treatments for melanoma until now and no significant breakthroughs for the last three decades and yet NICE has chosen to deny this treatment to sufferers and their families despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There has not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly improve the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced. By making this decision the effort and technology which has gone into this to date is wasted.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great. It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available immediately rather than within 3 months of the guidance being

	published
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in
Section 8 (Proposed date of review of guidance)	
Date	10/30/2011 5:22:00 PM

Name	David McLeish
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My friend is suffering from metastatic melanoma , the decision NICE has made regarding Ipilimumab is wrong. There have been no effective treatments for melanoma until now and yet NICE has chosen to deny this treatment to sufferers despite the fact that research shows that around 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. This has to be the standard in advanced melanoma treatment. I disagree with the assessment. I believe you have inadequately included melanoma affecting young people in the absence of any other effective treatment. There has not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. A new drug is obviously expensive in its infancy - only when this is widely available will the costs of treatment come down. This decision renders the effort which has gone into this thus far.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient

	population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great.It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available immediately rather than within 3 months of the guidance being published
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in
Section 8 (Proposed date of review of guidance)	David McLeish
Date	10/30/2011 5:09:00 PM

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

Name	Julie Rees
Role	Patient
Other role	NHS employee
Location	England
Conflict	no
Notes	Patients with choroidal melanoma a rare eye cancer metastasizing almost exclusively to the liver are exactly the group of patients who would benefit from ipilimumab. Choroidal melanoma is a genetic disease with biomarkers which would as Andrew Dillon said "identify this small group most likley to gain long term benefit" There is no other effective treatment for metastatic disease in this group of patients.Nice"s draft guidance against ipilimumab would assign survival to the financial elite,discriminating against these patients within the NHS in need of treatment. I believe treatment within the NHS to be free at its point of access.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The New England Journal of Medicine : Improved Survival with Ipilimumab i patients with Metastatic Melanoma , F Stephen Hodi 2/6/2010 Science Daily: Ipilimumab Antibody Therapy lengthens Survival of Metastatic Melanoma patients 7th June 2010 The Scientist Magazine of the Life Sciences :Taking aim at Melanoma Vol25 issue 4 page 32, 2011 The Pharmateller: B-MS ipilmumab shoes improved overall survival of patients previously treated with Malignant Melanoma June 2010 These articles are evidence against the committees recommendations
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	Ipilimumab is effective in choroidalmelanoma metastasizing almost exclusively to the Liver, These patients have biomarkers which "help to identify this small group of people most likley to gain long term beefit from receiving ipilimumab" & is "potentialy very effective for a small percentage of patients"
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/29/2011 11:08:00 PM

Name	Georgi Daluiso-King
Role	other
Other role	Daughter of Melanoma sufferer
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find it massively disappointing to read the provisional ACD. Finally we have found personal firsthand experience of a drug that can help fight such an aggressive cancer. No drug has been licensed since 1970 that actually expresses the potential to treat advanced melanoma like the ipilimumbab. I am shocked at the thought of this not being available to sufferers. I seriously question the integrity of the people behind this rejection of the drug. How can you contemplate denying those that have NO other options of treatment, the one treatment that has the ability to extend their lives by up to or over 1 year? Is one year of your life so meaningless to you that you feel you can take it away from those that may have nothing else? How can you even contemplate that? Where is your sense? Locked up in finances, that is where! It makes me think that the ACD is formulated by people that have never had firsthand experience of a cancer sufferer. If you have had this experience you would realise that a year of life is beyond cost, especially if the treatment itself does not cause suffering you have prolonged quality of life that is meaningful in every way. Our experience of ipilimumbab has not inflicted any adverse effects on my mother throughout her treatment. This has been a year of joy, a year of seeing her daughter marry, seeing her first grandchild, a year of walking in the dales and eating wonderful dishes in Italy! If I have read the ACD correctly, you have proposed that the expense of the ipilimumbab was not worth this year, was not worth this joy!!! I really question whether you have reached into your hearts and visualised the massive impact on patients, like my mother if this drug is rejected by NICE. How can the only therapy that has been shown to increase the 1 year survival rate compared to its comparator in a Phase 3 clinical trial be rejected? It is the only chance of survival that these sufferers have? It is not just one year that the ipilimumbab offers, but it also offers them the chance of further future treatments that are developing from the advancing technology and knowledge gained from these recent drugs that can work to improve survival. My Mother was diagnosed with malignant melanoma in 2006! This spread to her lymph nodes in her right groin. She was told then that she had up to one year survival. Then the dicarbazine trail became available. She responded. The cancer was completed irradiated and she lived on. We enjoyed so much together she was completely immersed in preparations for my

	woodland wedding where she laughed and danced all day and night. We have been on numerous holidays together and she has continued to support me like a loving mother that has no illness. A year ago the cancer came back. She was then offered the ipilimumbab. She again responded shockingly well. She had no adverse reactions and continued her life fully. During this time she has been able to enjoy the news of becoming a grandmother for the first time, and last week she came with me and my husband to meet her grand child on our first ultra sound scan. How amazing for all of us, let alone my Mar who has had to deal with a daunting prognosis twice and had let go of the concept of ever seeing her daughter marry, or meeting her grandchildren. Can you imagine having to deal with accepting that? Can you really? I don't believe you can if you still hold the value that the cost of a drug that gives you a year, just a year is not worth what I have described above. The ipilimumbab has given my Mar time. Time that opened a chance to see things that she thought she would never see, but also it gave and continues to give her hope and strength that she can fight this cancer. Look at studies that discuss the effect of positive mental attitude on health and you will see that those people do much better that those that have no hope. So, apart from the fact that this licensed drug offers a quality extension to life it also offers hope. I urge you seriously to reach into your hearts and consider the implications that you are suggesting with the removal of ipilimumbab from the reach of advanced melanoma sufferers. What you are considering is unjust and inhumane.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	Georgi Daluiso-King
Date	10/29/2011 10:06:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Current medication doest improve survival rates and is toxic. This new drug keeps condition stable and can cure in some cases. Treatment is used in England so why not here in Scotland. I am shocked as a health professional studying the disease that this drug is not available uk wide. This is grossly unfair and needs to be addressed.
Section 2 (The technology)	All drugs have adverse side effects
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	Its crazy that reassessment is not until 2015.
Section 8 (Proposed date of review of guidance)	
Date	10/29/2011 5:43:00 PM

Name	[redacted]
Role	other
Other role	[redacted] of Melanoma Awareness Project (Cornwall)
Location	England
Conflict	no
Notes	Our daughter died ([redacted]) from metastatic melanoma four years ago. When a brain tumour was diagnosed she was given two months to live and left without hope. She fought on for two years through alternative approaches using diet. This did give her hope and that is so essential when diagnosed with any terminal illness. Yervoy is the only new drug with the potential to delay death within melanoma patients. If this is not made available through the NHS - this would be a dreadful blow to those patients. Many of these are young people - and their number grows each year. We must do all we can to raise awareness, to speed up diagnosis, and to search for a cure.

	Please reconsider your decision. If you are denying this drug on the basis of cost effectiveness this is such a dreadful signal to those who are suffering - and those about to be diagnosed. There is no alternative. There is no hope! www.sun-safe.org www.melanomaproject.co.uk
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It would offer hope where there is none. For those suffering (and those about to be diagnosed)this hope could be the strength they need to pull themselves through. Many of these are young people.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/29/2011 12:06:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My brothers father in-law is currently suffering from metastatic melanoma. I find the decision NICE has made regarding Ipilimumab horrendous. There have been no effective treatments for melanoma until now and despite this NICE has chosen to deny this treatment to sufferers and their families. It is quite unbelievable that despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits this treatment is not unavailable. It seems you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There has not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust.However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option.It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great.It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available immediately rather than within 3 months of the guidance being published

Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug.Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in so
Section 8 (Proposed date of review of guidance)	
Date	10/28/2011 9:27:00 PM

Name	[redacted]
Role	Carer
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My father in-law is presently suffering from metastatic melanoma I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now and yet NICE has chosen to deny this treatment to sufferers and their familiies despite the fact that research shows that 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. This should be the gold standard in advanced melanoma treatment. I strongly disagree with the assessment. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy and the absence of any other effective treatment. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. Any new drug will be expensive in its infancy - only when this is widely available will the costs per treatment be reduced. By making this decision the effort and technology which has gone into this to date is wasted.
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. Evidence is clear that ipilimumab offers survival gain.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use

	of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people so overall cost is not great. It has been a three decade wait for a treatment breakthrough in advanced melanoma. Given the time and effort that has gone into this it is to be expected that costs are high.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available immediately rather than within 3 months of the guidance being published
Section 6 (Proposed recommendations for further research)	Unable to access these guidances to comment.
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/28/2011 6:12:00 PM

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

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)	My husband has just been diagnosed with advanced melanoma, this is his only hope for an extended life. He has worked his whole life has never been off sick and when he needs help he is being let down. His life will end at [redacted] years of age because there is nothing else that can give him hope
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/28/2011 5:49:00 PM

Name	[redacted]
Role	Private Sector Professional
Other role	Dental Nurse
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a family relative who has cancer and I know someone suffering from metastatic melanoma I find the decision NICE has made regarding Ipilimumab shcoking. There have been no effective treatments for melanoma until now. 30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. I therefore feel this treatment should be available to all cancer patients with advanced melanoma treatment. I strongly disagree with the QALY assessment. I feel that you have not taken into consideration melanoma affecting young people who work and raise families contributing greatly to the economy. There seems to be no direct cost comparison to current

	melanoma treatment. Ipilimumab is a landmark drug which could greatly affect the quality of lives of a small number of people. I feel it is unethical to withhold a treatment which could prolong a cancer suffers life. Surely NICE are effectively choosing which patients could survive or have an prolonged life expectancy with this decision.
Section 2 (The technology)	New drugs are usually expensive, however during time other companies will decide to produce this drug and therefore it will become more competitive and the cost will probably be lowered. Widespread and longterm use will lower costs as it is more widely available. Surely National procurement would remove cost variations and ensure a better costings. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma patients.
Section 3 (The manufacturer's submission)	If the drug is introduced as a form of treatment use will ensure larger numbers of users and enable more detailed data to be available. This will lead to discover those who will and will not benefit from this type of treatment. Ipilimumab offers longer survival rates considering the evidence.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. The trial evidence presented for this consideration seemed to be strong. The committee is in agreement of this aswell. Approximately 400/500 people with advanced melanoma progress onto second-line treatment each year in the UK. This is a small group of people and although costs per patient are high it is only for a few in comparison to many other treatments available to other types of cancer suffers. It has taken considerable time of bring to the forefront a breakthrough in melanoma treatment and surely this amount of time envolves to provide a better prognosis for patients is worth the expense and jusitifys the costs.
Section 5 (Implementation)	Treatment should be avaialable before NICE have even considered this as it is already denying patients a protential extended life. It is unethical to deny this drug to patients in Scotland when it is already available in some areas of England.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	It has been a many years for a treatment for menoloma and this drug is a breakthrough. Is beggars belief that patients should have to wait three more years for the use of the drug to be reconsidered, especially as it is already available in some areas of
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/28/2011 4:58:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	After hearing about the provisional ACD, I disagree with this decision. I understand and believe that Ipilimumab is the first drug for decades which is a treatment for advanced melanoma and as it can increase the 1 year survival rate for one of the fastest growing cancers in the UK I feel that this decision should be rescinded.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that Ipilimumab should be provided for treatment of advanced melanoma as it does have provable results of increasing the 1 year survival rate for affected people.
Section 2 (The technology)	The decision to provide Ipilimumab should be based on results rather than costs.
Section 3 (The manufacturer's submission)	My understanding is that the decision is not based on this ipilimumab treatment led to an undiscounted incremental gain in overall survival of 33.8 months compared with best supportive care. , but is instead based on this a 14% chance of ipilimumab being cost effective compared with best supportive care at £50,000. If this is the first treatment in years to provide effective increase in the 1 year survival rate then this decision should be overturned
Section 4 (Consideration of the evidence)	In consideration, the evidence seems to detail that the decision is about cost-effectiveness, however it would seem that it is purely related to cost of the treatment, and not effectiveness
Section 5 (Implementation)	n/c
Section 6 (Proposed recommendations for further research)	n/c
Section 7 (Related NICE guidance)	n/c
Section 8 (Proposed date of review of guidance)	
Date	10/28/2011 2:04:00 PM

Name	[redacted]
Role	Carer
Other role	
Location	England
Conflict	no
Notes	Why is malignant melanoma given such low priority when it comes to research and fundind? it is such an terrible disease and to see your loved one being eaten away by it is heart breaking.
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Why? Other forms of cancer are readily treated with drugs when in advance stages and this drug would meet an unmet need for this terrible disease.
Section 2 (The technology)	This drug is the first drug licensed since 1970 for the treatment of advanced melanoma. Even Nice accept this.
Section 3 (The manufacturer's submission)	Th
Section 4 (Consideration of the evidence)	Cases of advanced melanoma is increasing its all very well saying that people need educating in the need for sun protection but my very dear brother had the primary melamona on the ball of his foot!!! How can that be blamed on exposure to the sun. My brothers life was very precious and had he survived and had the chance of having this treated we would have been devistated if it had been refused.
Section 5 (Implementation)	Perhaps less money should be channelled in to drug & alcohol abuse which is self inflicted and more to conditions that develop through no fault of the patient.My brother was very precious and died too young because of lack of treatment and knowledge about
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/27/2011 11:20:00 PM

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

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find it inconceivable that oncologists will not be able to prescribe this drug. As a doctor I find this impossible to justify.Has an economic comparison been made between other cancers and their various drug expenses over the past 30 years?.There have been huge advances in breast cancer medical treatment in the past 30 years.Would this be the case if we had not prescibed the initial positive trial drugs? Specialists agree that new melanoma specific treatments will in the future allow a melanoma diagnosis to mean treatment as a chronic disease and not as a terrible prognosis. This will only be possible if clinicians with experience are able to learn from the experience of prescribing produce better treatments
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/27/2011 2:57:00 PM

Name	[redacted]
Role	[redacted]
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I disagree with the provisional ACD (Appraisal Consultation Document)
Section 2 (The technology)	This drug is the first drug licensed since the 1970s for the treatment for advanced melanoma and NICE themselves have

	acknowledged that this is a steep change in the treatment for advanced melanoma- so how can it not be offered to people in England and Wales?
Section 3 (The manufacturer's submission)	This drug addresses an unmet need. There will be a huge impact on patients if this drug is rejected by NICE. For example, this is the only therapy that has been shown to increase the 1 year survival rate compared to it's comparator in a Phase 3 clinical trial. Currently, there is little hope for those with advanced stages of this cancer, this new drug will provide those who previously had no hope of survival to fight their illness with an increase chance of survival.
Section 4 (Consideration of the evidence)	Evidence shows that the incidence of melanoma is increasing. Over the last 25 years, the rate of malignant melanoma in the UK has risen faster than any other of the top 10 cancers in the UK. It is the second most common cancer in the 15-34 age group. More than 11,700 people in the UK are diagnosed with malignant melanoma each year, so this type of cancer should be high priority on the list of medicine available for the treatment of cancer. More and more people will be in need of and could benefit from this drug.
Section 5 (Implementation)	Having experienced this cancer at close hand, it seems important that decisions about offering this treatment should not be made locally, but should be offered nationally so that your survival is based on where you live. Some authorities may consider
Section 6 (Proposed recommendations for further research)	Preventaion is better than cure and information is becoming more available and people are more aware. However, we are less protected from the sun rays due to environmental impacts that we are not in control of. We rely on the government to act on our behalf in the control of greenhouse gases, co2 emissions and other environmental pollutants. However, they are not keeping up with the amount of damage that has and is being caused. This form of cancer is a result of exposure to the sun, we can control this to some extent but the increasing need of care for people with skin cancer shows that there is more work to be done, and damage that has already occurred needs to be addressed and treatments made available.
Section 7 (Related NICE guidance)	It seems that February 2015 is too far away, and a review of the decisions made by NICE should come sooner. The outcome of their proposal does not seem to take into account the need of people, more the cost of treatment. How much is a life worth? Ho
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/27/2011 11:25:00 AM

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

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)	1) I am personally very disappointed to have just been informed of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. 2) This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. 3) If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. 4) This issue is important to you because organisations such as NICE should give all patients, regardless of illness, equal chances of survival. Prioritising treatment is unfair. I have 2 close friends who are directly impacted by this decision, and both of whom will leave young families behind. I pay taxes to ensure that healthcare is equally available to all. 5) Patient's hopes have been dashed. It is devastating that many patients have been left with little hope. I urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/27/2011 10:08:00 AM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	I absolutely disagree with this decision and implore this to be overturned. I appreciate drugs and care cost money but how

	can something be considered not cost effective if it can potentially save or prolong someones life. My mum passed away from a malignant melanoma and the disease took its toll very quickly and from diagnosis in early [redacted]! If there had have been any available treatment that may have prolonged her life we would have expected her to have it. If I was in this position now and the drug was there but she wasnt allowed it because it cost too much I would be beyond furious. As stated my mum passed away on the [redacted], her first grandchild was born in [redacted], she missed by about 6 weeks. I honestly know that was was no miracle cure for my mum and that this disgusting vile disease was going to kill her, but I would have given anything (my own life if it worked) for her to have survived long enough to meet her granddaughter. All she ever loved in her life was my brother and I and she was so excited to become a grandmother, she didnt even get to find out if it was a boy or a girl. Im sure shes looking down now and watching over [redacted] but its not the same. If she could have only met her and held her and looked into her eyes it would have made such a huge difference to all of us as this has been something both my brother and I have found incredibly hard to deal with everytime we look at [redacted]. Its make it even more unfair that we already thought it was. If there is a drug that can prevent this happening to other people and can give patients suffering from melanoma to have a better quality of life in their final days/months etc or can give them longer to say goodbye, meet family and friends then there is no argument against it. Cost should not be a factor...what value do you put on my mums life? on my nieces life to have never met her grandmother (how much nicer is that a story to tell her when shes older that her grandmother met her, held her and thought she was beautiful rather than no she dies just before you were born. I understand that these things happen and Ive worked hard to accept it but to now hear there is a drug that could have maybe kept her going long enough but she might not have got it coz it costs to much money makes me very angry. How much money is a life worth? To me you cant put a price on it. I hope this decision is overturned for all those suffering with Melanoma today.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	

Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/27/2011 10:01:00 AM

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

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 find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	
Date	10/27/2011 9:48:00 AM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/26/2011 9:14:00 PM

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

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)	I am devastated to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking and time-delaying decision by NICE and it is having a devastating blow to people with advanced melanoma whos remaining time is so very precious. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is extremely important to me because my relative is only 30 years old. She has advanced melanoma. She has 4 boys, three of whom are under 5 years old. It is devastating to the whole family and it is so vitally important that she manages with the help of this treatment to have as much time as possible with her 4 boys. She is so young. PLEASE help her. It is devastating that many patients have been left with so little hope. I urge you to review your decision. Yours sincerely, [redacted]
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/26/2011 9:31:00 AM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	FROM MY UNDERSTANDING UNTIL NOW THERE HAS BEEN NO TREATMENT FOR ADVANCED MELANOMA. THIS

recommendations)	NEW DRUG IPILIMIMUB HAS BEEN PROVEN TO KEEP THE DISEASE STABLE IN A VERY SUBSTANTIAL PROPORTION OF PEOPLE AND A CURE IN A SMALL NUMBER. I PERSONALLY KNOW A YOUNG FIT SUFFERER OF ADVANCED MELANOMA AND FIND IT EXTREMELY UPSETTING THAT HE CURRENTLY HAS NO HOPE OF GETTING TREATMENT DESPITE IT BEING AVAILABLE IN AREAS OF ENGLAND, EUROPE & AMERICA. I WISH TO EXPRESS MY EXTREME DISAPPOINTMENT IN THIS & HOPETHAT THIS WILL BE REASSESSED.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	ONCE THE DESCISION ON IPILUMIMUB HAS BEN MADE REASSESSMENT OF THE GUIDANCE IS TO BE IN 2015! THIS IS IS AN INCREDIBLE TIME FRAME TO ASSESS A RAPIDLY CHANGING SITUATION IN THE TREATMENT OF MELANOMA. I BELIEVE IT SHOULD BE REVISITED IN 2012 AT THE VERY LATE
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/25/2011 6:11:00 PM

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

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel that this drug should not be rejected on cost.THis drug could prolong patients lives and contribution to society and lessen the burden on the nhs.As with other advanced treatments the cost should be balanced against the benefits of prolonging peoples lives. I personally know one patient who would benefit from this and I feel very upset that I cannot help this person when there is an effective treatment
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/25/2011 5:53:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	As a member of public, a tax payer and friend of a melanoma patient, I wish NICE to review their decision insofar as this breakthrough in melanoma treatment ought not to be denied to patients. Standard treatments are proved not to work. NICE owe it to all patients, future patients and clinicians, to review this decision and make it workable. If that means that the drug company have to reduce costs, then so be it.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2	

(The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/25/2011 12:48:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Other
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I was very disappointed to hear about NICE's decision to deny the drug 'Yervoy' for individuals with advanced melanoma. A shocking decision that will affect the life expectancy of many with advanced melanoma. I hope that this preliminary decision will be overturned because all people (rich and poor) deserve to be able to fight their cancer battle with all that is available in the medical world.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/25/2011 12:35:00 PM

Name	[redacted]
Role	other
Other role	Friend of someone with Melanoma
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Ipilumimub has been proven to keep the disease stable in a substantial proportion of people and cure in a small number
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	

Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	Surely this should be reconsidered. 4 years seems a disproportionate time frame to revisit this drug especially when it is available in some partsd of the UK already
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/25/2011 9:08:00 AM

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

Name	[redacted]
Role	other
Other role	family member of melanoma sufferer
Location	Scotland
Conflict	no
Notes	I object to the fact that you are recommending that this will not be reviewed until 2015. This drug should be funded now to those who are suffering from this cancer. 2015 will be too late for them. Please reconsider your decision. Frankly, the drug company should be ashamed of themselves regarding the cost of the drug but so also should Nice for allowing it to be trialed in areas of England. This is discrimination towards everyone else in this country suffering from this disease.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	Coat should not be a factor and all four doses should be given to all especially when evidence has demonstrated that this has shown to be effective.
Section 3 (The manufacturer's submission)	This section should be more layman friendly for better understanding. Is it designed to put people off from replying? Cost should not be a consideration in denying people this drug.
Section 4 (Consideration of the evidence)	Evidence is more positive than ever before. This is a ground breaking drug and it would be tragic if not given to current sufferers of this dreadful disease. What if it was your child, parent, brother or sister? What would you want for them? You have your answer.
Section 5 (Implementation)	Cost should not be a priority when so many lives are at stake. Give the sufferers the drug and stop prevaricating. More money is spent in the NHS supporting people who have caused their own illnesses etc. Many of whom have not contributed to society but t
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	Time is of the essence for advanced melanoma sufferers. This should be revised by early 2012 at the latest. The proposed review is shocking when evidence has proved that this drug has shown a great degree of success in the treatment of melanoma.
Section 8 (Proposed date of review of guidance)	
Date	10/25/2011 1:01:00 AM

Name	[redacted]
Role	Public
Other role	

Location	England
Conflict	no
Notes	Just like to say that Im personally acquainted with someone whose relative has this awful disease and from what Im told this is her only chance. Difficult call to make in these tough financial times but feel that someone with terminal prognosis should be a priority in all circumstances. Subject is a mother of twins in her early 30s and thanks for reading.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/24/2011 10:00:00 PM

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

Name	[redacted]
Role	other
Other role	Family member of cancer sufferer
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	
Date	10/24/2011 9:06:00 PM

Name	[redacted]
Role	Public
Other role	

Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/24/2011 7:53:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people.
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	
Date	10/24/2011 7:48:00 PM

Name	[redacted]
Role	Public
Other role	

Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. It is a landmark drug which will greatly affect the quality of lives of a small number of people. As such it should be recommended for the treatment of advanced malignant melanoma in people who have received prior therapy . It t is wrong and unethical to withhold a treatment which is genuinely life extending. NICE have made a decision which is devastating and incomprehensible to many families.
Section 2 (The technology)	New drugs and technology is always expensive. Competition, widespread and long term use will lower costs. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma.
Section 3 (The manufacturer's submission)	Any survival gain is significant. Widespread immediate use will allow a more detailed data. This will allow us to discover those who will derive better/ lesser benefits.
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. It has been many years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable. Although costs per patient are high it is restricted to a small group of people
Section 5 (Implementation)	Treatment should be available nationally and immediately. A long wait period is both unacceptable and unethical.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This is a landmark drug which has taken over three decades to reach us. It is unacceptable that patients and families should have to wait over three years for this to be considered by which time this may be too late.
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/24/2011 7:45:00 PM

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

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Noted no new advances in 30yrs in melanoma treatment until now. We know have this new drug which shows good evidence of halting the disease progression. I think because of this new evidence this opportunity should be given to patients to help there symptoms and also provide evidence for future care of Patients with advance melanoma. Personally I know how this disease affects patients and their families. and personally know of a friend who is affected by a family member and feel should be offerred this treatment.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	feel strongly that re considering reviewing guidance in 2015 is far too long and should be reviewed within months.
Section 8 (Proposed date of review of guidance)	
Date	10/24/2011 5:16:00 PM

Name	[redacted]
Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I know a patient who suffers from advanced melenoma. I think that it is unethical that there is a proven treatment which is being withheld due to cost. I wish to make my views known publically.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	

Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	I think the time lapse for review is inappropiate and would be interested to know the publics view if this was reported in the press
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/24/2011 2:24:00 PM

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

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)	I am greatly disappointed to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma given the limited options for treatment currently avaialble. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. I am writing to you as I am concerned a drug proven to have worked is being rejected based on cost. This effects a close friend of mine who is currently fighting Melanoma. Please reconsider your decision and give some hope to melanoma suffers and a course of treatment that may prolong their lives allowing them to spend longer with their children, friends and families. Thank you.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/24/2011 12:15:00 PM

Name	[redacted]
Role	NHS Professional
Other role	Carer

Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a GP caring for patients with cancer and as a daughter whose father has metastatic melanoma I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now.30% of people treated with ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. Therefore It should be the gold standard in advanced melanoma treatment. I strongly disagree with the QALY assessment. I believe you have inadequately factored in melanoma affecting young people who work and raise families contributing greatly to the economy. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people.As a doctor I feel it is unethical to withhold a treatment which is genuinely life extending. It goes against the fundamental duties of a doctor. NICE have made a decision which is devastating and incomprehensible to our family
Section 2 (The technology)	New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. The adverse affects are acceptable considering the poor quality of life and prognosis of advanced melanoma
Section 3 (The manufacturer's submission)	Widespread immediate use will allow larger numbers of more detailed data. This will allow us to discover those who will derive better/ lesser benefits. There is no doubt that ipilimumab offers survival gain considering the evidence
Section 4 (Consideration of the evidence)	Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. The trial evidence presented for this consideration was robust. The committee is fully in agreement of this. Approximately 400/500 people with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a very small group of people. It has been over 30 years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. It is unethical that Ipilimumab is currently available in some areas of England due to the Cancer drugs fund which does not even exist in Scotland.
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	It has been 30 years for any breakthrough in treatment of melanoma. ipilimumab is a landmark drug. Is is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered

	particularly considering its use in
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/23/2011 9:50:00 PM

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

Name	[redacted]
Role	other
Other role	Realtive to cancer sufferer
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The decision made regarding Yervoy is appalling. There have been no effective treatments for melanoma until now and this drug offers sufferers real hope. This should be a big consideration for the NICE review. Even if this drug only helps a small proportion of sufferers surely this is enough? Giving life and hope to people is what the medical profession do and what motivates researchers to continue. Continuing this treatment will also be economically beneficial as this disease effects a large proportion of the young population who work and raise families. Not only should this drug be available to all relevant melanoma sufferers but the proposed date for review is far too long in the future and should be considered as soon as possible.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	The proposed date for review is far too long in the future. Many people will loose their fight with cancer during this time. People that could have benefited from the drug.
Section 8 (Proposed date of review of guidance)	
Date	10/23/2011 6:27:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Limited treatment options are currently available and there is no standard of care in this setting. Up until now, there have been no approved therapies for previously treated advanced disease.

	Dacarbazine, vindesine, interferon and carboplatin are amongst the treatments used but these offer limited benefit. None of these agents have demonstrated a significant survival benefit in randomised phase III clinical studies. The evidence of the trial strongly indicates that there is a genuine life extension with Ipilimumab. As such it should be recommended for the treatment of advanced (unresectable or metastatic) malignant melanoma in people who have received prior therapy.
Section 2 (The technology)	The most important adverse events are noted to be immune-related adverse events. The manufacturer's submission states that these events are manageable and reversible in most cases. The European Medicines Agency has accepted a pharmacovigilance programme proposed by Bristol-Myers Squibb to monitor and treat these events. Clinical opinion and recent trial data indicate that as clinicians become more familiar with the use of immunotherapy they are able to identify and treat these adverse events in a timely and proactive manner. New technology is always expensive. It is only with widespread & long term use that costs will decrease. A national procurement contract would remove cost variations and ensure a better price The costs estimated include wastage if a full vial is not used. Ways of reducing wastage should be considered.
Section 3 (The manufacturer's submission)	Any survival gain, whether 3.5 months or 27.5 months is significant. With widespread use more data will be available to derive those who derive greater or lesser benefit. As clinicians become more familiar with the use of immunotherapy they are able to identify and treat any adverse events in a timely and proactive manner which will reduce the incidence of events leading to death. Regardless of any weakness in the submissions of the manufacturer there is no dispute that ipilimumab offers survival gain to those affected by stage III & IV melanoma.
Section 4 (Consideration of the evidence)	The Committee was satisfied that ipilimumab met the criteria for being a life-extending, end-of-life treatment and that the trial evidence presented for this consideration was robust. However because it cannot be considered a cost-effective use of NHS resources it is unlikely to be a treatment option. It should be taken into consideration that only a small patient population (approximately 400/500 people) with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a small group of people. It has been a three decade wait for a treatment breakthrough in advanced melanoma. As such it is reasonable to expect that costs are so large.
Section 5 (Implementation)	While waiting on guidance from NICE treatment should be available nationally. Funding should be made available

	immediately rather than within 3 months of the guidance being published The link: www.nice.org.uk/guidance/TAXXX is unavailable
Section 6 (Proposed recommendations for further research)	Unable to access these guidances to comment.
Section 7 (Related NICE guidance)	Evidence already exists that treatment with ipilimumab is of benefit. It can provide an extended survival rate to people living with stage III and IV melanoma now. It has been 30 years since any significant breakthrough in treatment. It is unacceptable
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/23/2011 5:37:00 PM

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

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 this drug is the first real breakthrough treatment for advanced melanoma and it is devastating to discover that NICE has so far denied it. The currently available treatment for this disease dates back to the 1970s whereas so many other cancers have seen major advances in treatment. The disease afflicts a considerable number of younger people for whom an extension of life is extemely important, not least those who have young children. Any extra time they can spend with their children must be beneficial to those children. I urge you to reconsider you decision regarding this drug.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/23/2011 5:01:00 PM

Name	[redacted]
Role	Carer
Other role	Healthcare professional
Location	Scotland
Conflict	no
Notes	As a healthcare professional and a carer for my father, who has metastatic melanoma, I am hugely dissapointed by the decision not to approve Ipilimumab for the treatment of this condition. This drug offers hope for patients and carers to improve survival and its approval would make a difference to the management of melanoma patients and to the lives of many. Please review this decision.
Comments on individual sections of the ACD:	
Section 1	Ipilimumab offers hope for patients with advanced melanoma as

(Appraisal Committee's preliminary recommendations)	studies have shown improved survival in those treated with this drug. As such it should be approved for use. If this drug is not approved it compromises patient care and affects significant numbers of patients and their families. Please review this decision and allow our families to access this drug.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/23/2011 3:30:00 AM

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

Name	[redacted]
Role	Patient
Other role	
Location	N Ireland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am disappointed at the decision of the Committee to not recommend this new treatment. I am a 28 year old Stage 4 malignant melanoma patient. I currently have metasteses to lungs, liver and bones and as there are very few treatments available I feel that this recommendation has limited the possibilities for me in receiving treatment. I believe that I should have as much right as any other patient in accessing treatment that has been shown to be effective and given that there has been so little advancement in melanoma compared to other cancers, I really do feel that my life is at risk by this decision. At this point standrad chemotherapy is the only option available on the NHS as standard practice but it is widely agreed that this is generally ineffective. I am not ready to give up on my life. I dont understand why at 28 years of age I have to consider that no treatments are being made available to me. I have worked hard and paid my taxes and should be able to avail of the NHS in my time of need. I have decided not to take the dacarbazine therapy given that this drug is now not available as a second line treatment. I urge the committee to reconsider.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/22/2011 4:23:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England

Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I would just like to let you know that as an advanced melanoma sufferer I am extremely disappointed to hear of NICEs decision that the Yervoy drug has been declined. This is a shocking decision by NICE and a significant blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will have limited treatment options beyond the standard of care which is basically Dacarbazine which we know is only 20% effective. This issue is very important to me as having almost completed a course of Darcabazine I am aware that the only follow up options and hope of extending my life is to have this Yervoy drug of one of the BRAF inhibitor drugs that are being trialled. I have heard of many people who have had excellent results when being treated with Yervoy and now suddenly patients hopes have been dashed. It is devastating that so many patients have been left with little hope, therefore I urge NICE to rethink its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/22/2011 1:21:00 PM

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

Name	[redacted]
Role	Patient
Other role	
Location	Other
Conflict	no
Notes	I have been receiving ipilimumab (now known as Yervoy) since 2006 in two separate clinical trials. Those of us with otherwise untreatable Stage 4 Melanoma NEED and deserve the chance to try this therapy. Our alternative is pretty much a death sentence.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	In my case, I had prior therapy, a chemo drug called temozolomide. I understood that the research was supporting the fact that the combination might have actually helped.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	I have survived 5 years so far. I am still in a maintenance phase trial for the sole purpose of providing data for organizations like yours to see that it works!
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/21/2011 9:33:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am very disappointed to hear of NICes decisionthat the new drug-Yervoy- for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because I have melanoma and I have had for 3 years, in the last 2 months it has returned again

	and awaiting treatment, I am married and Have 2 children one 19 one 15, the stress and strain this causes on family life is with doubt awful and would not wish it on anybody else please overturn your decicsion for my family and everybody else who is suffering this awful disesae. Patients hopes have been dashed. It is devastating that many patients have been left with little hope.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/21/2011 11:05:00 AM

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

Name	[redacted]
Role	Public
Other role	
Location	US
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is a shocking decision by NICE and a devastating blow for people with Melanoma.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/20/2011 6:54:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	For patients such as myself with stage IV malignant melanoma this drug offers us a real fighting chance against this aggressive disease. When i was diagnosed 6 months ago my world fell apart as being a health professional as well I knew that my options were limited and my long term survival was poor. I have young children that I want to see grow up and I believe that every patient has the right to the most advanced treatments available. We have one of the worst cancer survival rates in the World and I thought this government was committed to improving this!!!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	

Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/20/2011 2:01:00 PM

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

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am disappointed to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. I find this decision by NICE shocking and I think it is a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because I have been treated for Melanoma this year. I have between 15 and 70 percent chance of this disease recurring and I may find myself in the future as a patient with advanced Melanoma so this drug could be very important in my own future if I am unlucky. I am writing to NICE because I am concerned about this decision as a patient treated for Melanoma. There are many patient's whose hopes have been dashed. It must be devastating for them as without access to this drug patients have been left with little hope of effective treatment. I would urge NICE to please reconsider their decision regarding the drug Yervoy (Ipilimumab) for the sake of all patients, including myself, in future.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am disappointed to hear of NICE's decision that this new drug ' Yervoy ' for people with advanced melanoma has been denied. I find this decision by NICE shocking and I think it is a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because I have been treated for Melanoma this year. I have between 15 and 70 percent chance of this disease recurring and I may find myself in the future as a patient with advanced Melanoma so this drug could be very important in my own future if I am unlucky. I am writing to NICE because I am concerned about this

	decision as a patient treated for Melanoma. There are many patient's whose hopes have been dashed. It must be devastating for them as without access to this drug patients have been left with little hope of effective treatment. I would urge NICE to please reconsider their decision regarding the drug Yervoy (Ipilimumab) for the sake of all patients, including myself, in future.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/20/2011 12:09:00 PM

Name	[redacted]
Role	[redacted]
Other role	Patient
Location	Scotland
Conflict	no
Notes	[redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As the daughter of a patient who has stage 4 malignant melanoma I am dismayed with NICEs preliminary recommendations. My [redacted], apart from the tumours in her lungs she is a fit and healthy woman, who should have her retirement to look forward to. Instead she is faced with the fact that if her current chemo doesnt work she is left with no other choices of treatment options and will be left to face this battle with melanoma without treatment. Although Ipilimumab is expensive, how does this compare to the cost of treating patients with advanced melanoma, treating the new tumours that appear through surgery, chemo or radiotherapy? Would it be more cost effective to give Ipilimumab at stage 3 to stop the disease progressing? In my Mums case (and others I suspect) melanoma was only diagnosed after numerous visits to health professionals over an 18 month period, in which Mums concerns about her foot were dismissed as being a verucca, when in fact it was melanoma, who knows what would have happened if Mum had been diagnosed at the start. Mum was failed by the NHS then and is being failed again now by not being given the chance to access this drug

	which could save her life.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/20/2011 11:37:00 AM

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

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 rethink this appalling decision, what about the young women who need to see their children grow up!!!
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/19/2011 2:40:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is disappointing that NICE have taken this prliminary decision. As the first treatment to show significant patient benefits for 30 years, there are many disillusioned patients who were looking for a positive response from NICE. Accepting that there has been limited trialing and long-term studies for this drug, there is no doubt that it can have a dramatic effect on patients length and quality of life. Cost to NHS resources is obviously the major factor, Melanoma has exploded as a condtion in the UK and without treaments like Ipilimumab being made available, the cost of normal patient care will be huge. I urge NICE to re-consider their recommendations.
Section 2 (The technology)	
Section 3	

(The manufacturer's submission)	
Section 4 (Consideration of the evidence)	One could argue that, despite no signicant long-term follow up of the treatment, the initial results have been so dramatic in certain patients, of whom ther will be many in the UK, this drug needs to be made available as quickly as possible to the wider community. As a matter of course, as with any product, costs will be reduced per patient as volume increases. This drug has given hope to very many people whose prognosis without it is poor. Licence this product and let NHS procurement fulfill its role.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/19/2011 12:29:00 PM

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)	I believe this decision has been made on a cost v benefits basis. I understand fully that there are not unlimited resources available to the NHS but in trials this drug has worked for many and cured a few. In this respect it has given hope to many of us cursed with this awful cancer, which has not seen any innovation in treatment for 3 decades. To that end I would ask that you carefully consider the following question What price a life?
Section 2 (The technology)	Results from trials have been encouraging. This new approach to the treatment of these types of cancer is truely revolutionary and the risk of the side effects is miminal compared with the alternative.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/18/2011 8:58:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am very disappointed to hear of NICE's decision that the new drug ' Yervoy ' for people with advanced melanoma has been denied. This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard

	of care. This issue is important to me because I am a patient with Stage 4 Metastatic Melanoma. I am terminally ill, but believe that as a 39 year old mother of two young children (aged just 6 years and 17 months respectively)I have the right to live as long as possible to be there for my children. I am still fit and active, I work, contributing to this countries economy and the NHS, just as I have done since I was 16. Yervoy could more than double my life expectancy. Do you want to explain to my six year old son why his Mummy cant live for even 6 months longer? Patient's hopes have been dashed all across the country. It is devastating that many patients have been left with little hope. I urge NICE to review its decision, for me and for my children and for all the other patients across the country just like me.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/18/2011 3:38:00 PM

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

Name	[redacted]
Role	Public
Other role	
Location	Other
Conflict	no
Notes	I am very disappointed to hear of NICE's decision that this new drug 'Yervoy' for people with advanced melanoma has been denied.This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to me because my only sister died 2 years ago from advanced melanoma leaving behind 2 little girls aged 7 & 9. If she had had access to "ipilimumab" perhaps shed be around to see them grow up and be there for them. I know its too late for them but perhaps it can help others like her. Living witht he certaintly of death within a year, that is protracted and painful is difficult enough. But now patient's hopes have been dashed. It is devastating that many patients have been left with little hope. Please NICE to review its decision.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	That you are disappointed to hear of NICE's decision that this new drug 'Yervoy' for people with advanced melanoma has been denied.This is a shocking decision by NICE and a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned then patients will continue to have limited treatment options beyond the standard of care. This issue is important to you because my sister died of melanoma 2 years ago, at a young age leaving behind 2 young daughters...its too late for her but it could help other families who are distraught at having to have a prolonged agonising death without much hope of treatment if this drug is not recommended. Patient's hopes have been dashed as there are so few drugs or treatments avavilble for melanoma. It is devastating that many patients have been left with little hope. Please, I beg of you to reconsider your decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5	

(Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/17/2011 6:18:00 PM

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)	From a personal perspective, I am presently on a clinical trial, recommended by my Oncologist, which I pray and hope has the desired effect. In trying to remain positive and determined to beat my illness, much of that hope was based on the offer of all available treatments when I was first diagnosed, Yervoy being one. Albeit I am in the midst of treatment should I need to consider an alternative treatment, I sincerely hope that the decision of NICE is reversed, as I and many others would find it somewhat unbearable to have that hope interfered with or removed. On advice of my medical team, this recommendation now excludes me from treatment. On what basis was this decision arrived at?
Section 2 (The technology)	Clearly this decision is based on the cost of the treatment, some £75,000. I have to say, whatever the cost, should the circumstances allow the treatment to be utilised to save or extend a life, should cost play a part. Understanding that it does, as a one off payment for this treatment, surely given the success of this drug, this is inexpensive when compared to many other treatments/surgical procedures that are already available on the NHS. Statistics associated with Dacarbazine, the traditional treatment are extremely limited in success. Perhaps money could be saved by removing DCIT from first line therapy, which could be spent elsewhere.
Section 3 (The manufacturer's submission)	Understanding the evaluation of models that have been put forward for consideration, what should not be forgotten in these assessments of what is virtual is that Yervoy is the first treatment for more than three decades that can be truly considered to be a breakthrough in advanced melanoma. My research has revealed that many new treatments are being trialled presently, and should they prove to be successful, should individuals who have had their life extended by the drug Yervoy, then it may very well mean that other treatments being currently tested become available to treat or cure them.
Section 4 (Consideration of the evidence)	I am newly diagnosed and have learnt a great deal in a short space of time in relation to this illness. Understanding what is being said above, in that where previous therapy has been

	applied, this would need to be better explained, as my understanding is that current first line therapy is DCIT, by following existing practise, this would immediately discount many patients. I would therefore respectfully suggest that if access to Yervoy can still be made, but only where no other therapy has been applied, a period of time would need to be allowed to elapse in relation to those patients who have had to follow existing process, that is DCIT, this recommendation is unclear in this respect and needs to outline changes to existing practise that will be required. I understand that the next para deals with this, but it should be made clear in the recommendtaion.
Section 5 (Implementation)	I have no comment to make other than decisons should in any event remain local and take into the circumstances of each. In effect each case on its own merits.
Section 6 (Proposed recommendations for further research)	No comments to make, other than to reiterate a period of time should be allowed to elapse to allow patients who are in the system to be able to gain access to this treatment, should the circumstances allow and that this decision, should remain a local one.
Section 7 (Related NICE guidance)	This review should be brought forward on the basis on evidence that might come to light and other treatments that may very well become available. i would suggest that the review remains flexible, in other words February 2015 or sooner should other evidenc
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/17/2011 6:01:00 PM

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

Name	[redacted]
Role	Carer
Other role	
Location	US
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The decision for treatment should be between the patient and the treating physician and not any regulatory agency or government.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	The decision for treatment should be between the patient and the treating physician and not any regulatory agency or government and not predicated on cost.
Section 8 (Proposed date of review of guidance)	
Date	10/17/2011 5:18:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As per the experts leading the field in the research of melanoma, such as my own consultant [redacted], this is the best treatment to have shown actual tumour shrinkage and life extension, for 30 years...I am shocked that N.I.C.E have blocked this treatment when it is the proven best treatment there is for advanced melanoma and the only lifeline to advanced melanoma patients. When this treatment made its way to the world press and other countries endorsed its use, it was a ray of hope for melanoma patients. I am disgusted that the NHS will not be using it as standard care until another treatment becomes better and is proven to extend lives for longer. Another UK embarrassment.

	Please rethink your decision and save some lives. I was an the avastin trial for stage 3 patients to see if it may prevent a recurrence...I was not told that going on this trial to help the research for a cure, would mean I would be unable to get access to better treatment should it become available....
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/16/2011 7:56:00 PM

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

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a stage 4 advanced melanoma patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As an advanced melanoma patient I am devastated that access to Yervoy has been denied. I have been given one year to live without treatment. I am currently on another trial drug which works well, but does not have longevity. I hoped to go onto Yervoy when my presnt drug stops working, and Yervoy was my hope for several more years of life. Without Yervoy there will be nothing for me once my current drug stops working (Which is statisitcally after 7 months). At present I lead an active life and am still working, so to think that my life will end in one year (Unless I can access Yervoy), is devastating. Obviously I am shattered by the NICE decission not to allow the NHS to use Yervoy and I beg you to reconsider. I am aware the cost is high, but unless new drugs are used, there will never be any cure for Melanoma found. The effect on cancer patients, to know there is an effective drug available, but to be denied access to it, is very cruel, and not something I would expect in an advanced country such as ours. Please please reconsider.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/16/2011 6:42:00 PM

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

Section 1 (Appraisal Committee's preliminary recommendations)	This shocking decision by NICE to deny Yervoy is a devastating blow to people with advanced melanoma. If this preliminary decision is not overturned patients will continue to have limited treatment options beyond the standard of care. I was diagnosed with melanoma at the age of 38 & then at the age of 51 it returned, having spread to my lymphatic system & I am now Stage 3b. At the time [redacted] & was looking forward to a new chapter in my life. I am now the sole carer for my elderly mother-in-law who has dementia and my biggest hope is to see my newest grandaughter who was born in Australia 8 months ago. Therefore any drug that would prolong my life would be a godsend to me. Also, my only sibling at the [redacted] have had dysplastic moles (pre-cancerous)removed & may also be at risk of contracting melanoma. This decision is therefore a blow to my whole family. Patients hopes have been dashed and it is devastating that many have been left with little hope. I therefore urge NICE to review its decision.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/16/2011 4:03:00 PM

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

Name	[redacted]
Role	Public
Other role	mother [redacted]
Location	England
Conflict	no
Notes	My [redacted] has had malignant melanona thankfully she is now recovered fron it but it is always at the back of your mind and as a family this is something we have to live with also my brother works for the factor 50 charity and hears horrible stories on a daily basis so i would urge you to please think again about not letting this drug be allowed to people who need it. [redacted] [redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	10/15/2011 3:07:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	Can the cost of the drug not be reduced? How can 4 infusions possibly cost £72,000!!! NHS money is frequently wasted to give drug addicts drugs, they chose drugs, we cancer patients choose LIFE!!! NHS money is also frequently wasted on sex change operations. We cancer patients dont care what sex we are, we want to live to watch our children grow up!!! Smokers, who choose to smoke are treatrd on the NHS. I am a non smoking Melanoma patient who has never used a sunbed or sun worshipped and as I have two young daughters to raise I cannot afford £72,000 for life saving drugs.
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	[redacted]
Date	10/14/2011 5:37:00 PM