327 copies of the following letter were sent to NICE.

The senders were either people with prostate cancer or friends and relatives of people with prostate cancer.

5 individuals added personal notes to the text. These 5 letters are also included in these papers.

[redacted]

Mr Jeremy Powell,
Abiraterone Technology Appraisal Project Manager
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

9th February 2012

Subject - Abiraterone appraisal consultation

Dear Mr Powell,

I have read that Abiraterone has been rejected by NICE and will therefore not be available to NHS patients. I find this hard to understand as it is a very successful drug which has been proven to work.

It has the potential to increase life by years, not just 4 months. During the 9 month trial, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence the quoted 4 months of extra life, this seems to be misleading as the actual life extension will probably prove to be much longer.

It has the ability to help men to keep in employment and not have to claim benefits because of ill health. It is very easily administered, just 4 tablets per day, at home (or anywhere else you may be). This must reduce the overall cost to the NHS.

It gives a greatly increased quality of life with much reduced pain and has very few side affects

There are no alternative treatments available; the only alternative is no treatment and death.

As a Prostate Cancer patient I am obviously very worried that a drug that has been proven to work on Prostate Cancer is not being accepted due to the costs involved. NICE do not appear to have taken into account the fact that the drug is administered at home by the patient and that the costs of the treatment will reduce over the life of the drug.

I ask that NICE reconsider their decision to reject Abiraterone and instead licence the drug for general use where considered clinically appropriate without further delay.

Yours faithfully,

[redacted]

[redacted]
sept 2011, he was only 62. a usually very healthy man. If this drug can help other men's lives and stop children losing their parents at such a young age it's disgusting it is not availbe on the NHS.

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Recd 14/02/12

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Yours faithfully,

[redacted]

(Daughter of [redacted] Passed away sept 2011 after a 7yr battle with prostate cancer)

[redacted]

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P.S. MANIPULATING STATISTICS IS EASY, BUT YOU CAN'T MANIPULATE DEATH.

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Yours faithfully,

[redacted]

[redacted]

This drug could have helped my husband who died from Prostate Cancer 2 years ago on the 17th of march. Please do nd deny other patients.

[redacted]

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I ask that NICE reconsider their decision to reject Abiraterone and instead licence the drug for general use where considered clinically appropriate without further delay.

Yours faithfully,

[redacted]

I would add that I'm one of the lucky ones My prostate cancer was dragnosed early enough for a successful laparoscopic radical prostatectomy to take place If I'd not been dragnosed that early, I'd be at risk of too premature a death of denied abiraterone.

[redacted]

O.A.P. + PROSTATE CANCER + (CARER 45 yrs) SEVERELY HANDICAPPED DAUGHTER + PLUMBER HEATING ENG. 55yrs "YES" 55yrs PAYING TAX + AND HELPER FOR MY WIFE 70+ O.A.P.

Mr Jeremy Powell,
Project Manager
National Institute for Health and Clinical Excellence
MidCity Place
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So you see on your fat salary you are not condemning one person to death, it's (3) in this case, cos they will not be able to manage without me and will cost country much much more in care home.

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YES 55yrs Work + 45 yrs Carer = 100yrs Work

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I ask that NICE reconsider their decision to reject Abiraterone and instead licence the drug for general use where considered appropriate without further delay.

Yours faithfully,

CHESHIRE PROSTATE CANCER SUPPORT GROUP - LEIGHTON HOSPITAL CREWE.

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

Role	NHS Professional
Other role	on behalf of NCRI Prostate Clinical Study Group
Location	England
Conflict	no
Notes	I am submitting additional data on behalf of the NCRI Prostate Clinical Study Group.
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)	In response to the cost effectiveness concerns over abiraterone, NCRI Prostate CSG members and others have formed a Trial Management Group and submitted a trial application to the HTA. FASTRAC is a trial which exploits the abiraterone food effect. Abiraterone has the most marked food effect of any drug in medicine. Bioavailability is increased five to ten fold if the drug is given with a meal. Yet the manufacturers recommend that four tablets (1000mg) be taken on an empty stomach. In FASTRAC we propose restricting abiraterone to a cost effectiveness trial, in which one tablet taken immediately after a meal is compared to four tablets taken on an empty stomach. This trial would save over £19million in drug costs and would be a less costly route to providing access to abiraterone. One option for the NICE panel would be to liaise with the HTA and recommend abiraterone only within the FASTRAC trial. This would link the research and policy arms of the NHS for the first time and provide a new approach to the provision of costly new cancer drugs. The full HTA FASTRAC protocol is available on request from the Prostate CSG Chair.
Section 5 (Implementation)	
Section 6 (Related NICE guidance)	
Section 7 (Proposed date of review of guidance)	

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Not recommending a drug that works for people is foolish and selfish on the committees part. We are discussing the possibility of helping people cope with a very painful disease. If a drug of any kind works to aide this, it should be made available to them. If a drug is working for a patient, taking them off it to start them on another would be a ridiculous thing to do. The drugs should only change when the one they are on as stopped working for them.
Section 2 (The technology)	Abiraterone should be made available to patients when: All drugs have side effects, but most of the time the pain prior to being on treatment is much worse. Prostate cancer pain is so unbearable at times, the patient reaches a point where they consider ending it all. They cant move, they cant sleep, they cant eat, they cant live. They arent living, so self termination seems like the only answer. But then

	a drug is given to them and it works, life begins again for them. They can now do the simplest of things that people take for granted, like walking down the street, watching TV comfortably on the sofa, taking the dog for a walk, even having a day out with their partner or family. Abiraterone is a pill, so how can it cost £2,930 for 120 of them?
Section 3 (The manufacturer's submission)	Abiraterone is obviously the best available drug for patients with Castration-Resistant Prostate Cancer after Docetaxel has stopped working for them, With all the trials proving that it improves quality of life. It also provides them longer existence, less pain, decreased risk of progression and survival advantage. Also any side effects relating to Abiraterone have been proven to be either treatable, or reversible. It is also a better drug compared to Mitoxantrone and more cost effective. Not having to go to the hospital is also a great advantage to the patients, as it means they can try to live a normal life with Prostate Cancer.
Section 4 (Consideration of the evidence)	With all drugs the body gets used to them and in some cases the drug can stop working for that disease. Hence the reason Abiraterone follows on from Docetaxel. So although the committee considered Abiraterone was not licensed for a small population, the fact is, that cant be proved. As some patients can continue with Docetaxel, some will then go onto Cabitaxel, then onto Abiraterone. So the actual amount of people on each drug Is an estimated guess based on the amount of people with Castration-Resistant Prostate Cancer and the amount of people that were used in the trials. So for NICEs supplementary advice, the end-of-life criteria that had to be met, 2 of the 3 were demonstrated throughout the trials. The small patient population could be met depending on how each patient takes to each drug available to them. Although even if all 3 had been demonstrated, The Committee have concluded that they still cant justify Abiraterone as an appropriate use of limited NHS resources. That in itself is a stupid, ridiculous excuse to not recommend it to the NHS. Abiraterone is a pill that is taken by the patient in their own home and not with Chemotherapy. Saving the NHS money for beds, nursing care and time, Chemotherapy ward staff and chemotherapy beds, blood tests and steroids. As well as any call outs and care given to patients because of the chemotherapy side effects. Also patients dont want to be in the situation they are in. No-one wants to feel weak and helpless. So having a drug that can work for you, and being able to take it at home, gives the patient independence and dignity again.
Section 5 (Implementation)	Funding shouldnt be an issue when it comes to cancer treatment. Its a disease not brought on by fault, even though some blame smoking, but my partner had cancer in her leg when she was 5 and obviously she didnt smoke. So it just grows in certain people for reasons still unexplained. Therefore, cancer isnt a choice for people, unlike drug or drinking abuse, abortions and STDs, but all these things get treated without question. These could be stopped by the individual people not doing them in the first place, saving the NHS money to go towards victims of diseases etc. Also, were talking about NHS funding. Care and treatment should be available to British citizens regardless. We pay our taxes and National Insurance. So any treatment needed that works should be there. The treatment of Foreigners coming into our Country to abuse the NHS shouldnt be allowed, which would have saved the NHS at least £75 million last year alone. It is National Health Service, not International Health Service. If a person hasnt contributed to the British Tax and National Insurance, care shouldnt be allowed and should be a bill they pay for, like in America. Its not fair to make people who have worked and paid there way then pay for treatments, especially when its of no fault of their own.

Role	Patient

Other role	Local Government Accountant
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	NHS is supposed to put patient first so patient and his clinician should make final decisions as to what is best
Section 2 (The technology)	Side effects are probably outweighed by the benefits and time is of the essence, ie not long to live
Section 3 (The manufacturer's submission)	The effect may be marginal in our time terms but in the terms of the patient it is a lifetime
Section 4 (Consideration of the evidence)	I think it should be provided on the NHS and is descriminatary compared with aesthetic treatments which the NHS provides free of charge
Section 5 (Implementation)	even with limited funds the total cost over the time period of life is not greatly significant
Section 6 (Related NICE guidance)	More emphasis needs to be given to prosttate cancer, a major killer of men
Section 7 (Proposed date of review of guidance)	Needs to be reviewed immediately, treatments are moving so fast and many men do not have time

Role	NHS Professional
Other role	senior lecturer in urological oncology
Location	England
Conflict	yes
Notes	I worked on the pivotal phase 3 studies of prednis(ol)one +/- abiraterone in prostate cancer. Our department was refunded on a per patient basis.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Abiraterone is a treatment which is given by mouth, is well tolerated by patients, improves symptoms and prolongs time to deterioration of symptoms in metastatic prostate cancer patients who have failed docetaxel chemotherapy. It prolongs median survival by almost 5 months. This is a patient group where other treatments are almost always ineffective. Of course patients want to have this treatment despite the limited duration of benefit and there will be great disappointment if they do not have access to it. I note the high ICER number. I also notice that the end-of life rules do not apply as this group of patients is too large: ie patients are penalised because there are too many in their situation.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Completed 37sessions of radio therapy for prostate cancer.Now in remission and eighteen months in to hormone treatment to keep PSA levels down.Retired RAF engineer officer, age 78yrs.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agree recemmendations
Section 2 (The technology)	To a non medic The technology appears sound.Easily administered via four tablets a day is a plus.
Section 3 (The manufacturer's submission)	On the manufactures evidence alone Abiraterone is expensiv however the survival rates in comparison with other drugs are good.
Section 7 (Proposed date of review of guidance)	I am not aware of the actual number of patients benefiting from Abiraterone at this time I suspect relatively few.On this basis although costly I feel strongly that the

	availability of this drug should continue beyond 2014. It extends life, in certain circumstances enables patients to continue working. As noted above easily administerd. Obvious from the report that there can be side effects. However,the one person I know on this drug has reported none. My experience with side effects is that I would rather have them than death. Finally, it is apparent that alternative treatments are not available on this basis it should be retained as the final last chance treatment for prostate cancer.

Role	Private Sector Professional
Other role	widow of prostate cancer patient
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I would like to see patients to use this treatment under the guidance and advice of their clinician at the end of the day he only is able to evaluate the life expentancy and value of this drug to the patient.I think it should be at their descretion

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have regular contact with other patients,including some with advanced prostate cancer.Abiraterone is seen as the treatment of last resort when all else has failed.To withdraw this drug will be a cruel blow.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	We do not think all the relevant information has been taken into account. The potential to increase life by years, not just 4 months. During the 9 month trial nobody on the drug died. Men receiving a placebo trial started to die after 5 months.
Section 2 (The technology)	We feel that prostate cancer has a much lower profile compared to other forms of cancer. Using this drug has the ability to help men to stay in employment and not have to claim benefits because of ill health
Section 3 (The manufacturer's submission)	Men using this drug live longer and in better health
Section 4 (Consideration of the evidence)	Using this drug greatly increased quality of life with much reduced pain, helps keep man working and contributing to the economy.
Section 5 (Implementation)	Easy to administer and be taken at work or home. Very few side effects.
Section 6 (Related NICE guidance)	No alternative treatments available. The alternative is DEATH. THIS IS A "NO BRAINER" why not let those who are seriously ill have life saving treatment?
Section 7 (Proposed date of review of guidance)	Reconsider the statement used to the media which we believe to be incorrect. The potential is to increase life by years not just months as trials have shown.

Role	Carer
Other role	

Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that patients should be offered abiraterone treatment as an option because any extension to life and improvement in their quality of life is so important and meaningful to those affected, their families and friends. I understand that cost has to be considered in the decision making process but when the person that you are talking about is someone whom you love dearly then the benefits are immeasurable.

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	This life-extending treatment should be available to every man suffering from this condition at the final stages of their life to give them those precious last moments to spend with their loved ones.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	continue this life extending treatment in all men at the final stages of their life

Role	other
Other role	Chartered Chemist and patient
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have been following the development of abiraterone for some years. It is the result of a designer drug process, and I expect this approach to become more important in future. It is likely that with contiued use a sub group may be identified which can use abiraterone more cost effectively. This will only be discovered if the drug continues to be made available. As a prostate cancer sufferer I would be very sorry to see this development ended prematurely.
Section 2 (The technology)	As far as I can see, the side effects of this treatmnent are lower than some alternatives. Cost seems to be the main contraindication.
Section 4 (Consideration of the evidence)	It seems unfair that sufferers with short life expectancy and good prospects of extension to life should be denied an effective treatment simply because they are not a small group.
Section 5 (Implementation)	Cancer of the prostate is a poor relation in terms of public concern and awareness- it is clear that this treatment is at present quite costly, but one can reasonably expect that cheaper and more effective treatments will emerge over time. In the meantime I urge that this treatment is made available to sufferers who may benefit now.

Role	Public
Other role	Daughter of patient
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe abiraterone is the only option available for these patients that offers life extension and delays disease progression. Please approve its use at least until an alternative therapy is found.
Section 2 (The technology)	The drug provides hope as well as treatment where none is available at present. It

	should be approved.
Section 3 (The manufacturer's submission)	The manufacturer should reconsider pricing to make it more affordable However this is the only hope for many men to extend life with good quality of life.
Section 4 (Consideration of the evidence)	Should the STA recommend abiraterone for use for this indication, it will help to provide standardised access to the drug, increase the range of clinically effective treatment options available to all patients for whom it is appropriate and provide them with greater choice and hope, possibly giving them more time with their families and improving their quality of life.
Section 7 (Proposed date of review of guidance)	There are currently no other treatments widely available on the NHS across the UK for men who have metastatic castration-resistant prostate cancer which has stopped responding to hormone therapy and chemotherapy. The only other options are palliative. Please reconsider this drug.

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	In addition to my professional role as a registered nurse working with individuals with advanced cancer including cancer of the prostrate I feel that it is important to mention that my father was also diagnosed with stage 4 N1 Ml Gleason 9 prostrate cancer 18 months ago.He is currently responding well to Zoladex but we are all well aware that it is only a matter of time before this regime stops working and other options need to be considered.I am in regular communication from men around the world who have been lucky enough to respond very well to Abiraterone and in some cases this drug has dramatically transformed these individuals lives for the better, giving them very good quality of life for significant periods of time. In my opinion you cannot put a price on this? My father is only 59 yrs old and prior to this has never been ill or cost the NHS anything. Like many others he has worked hard all his life and deserves to be given the opportunity to remain well and pain free for as long as he possibly can. (as of course does everybody else in this situation!)
Comments on individual sections of the ACD:	

Role	Patient
Other role	Local prostate cancer charity volunteer
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is inconceivable to me that this recommendation is made when I have witnessed such a dramatic positive effect on a patient.
Section 2 (The technology)	It is my opinion that too much weight has been put on the adverse reactions. The cost appears to be very inflated and should be dramatically reduced if it where to to be used on a larger scale.
Section 3 (The manufacturer's submission)	Whilst obviousley with a strong vested interest I believe the manufacturers submission to be accurate
Section 4 (Consideration of the evidence)	I consider that the evidence has not been sufficiently considered and a wrong disision has been made.
Section 5 (Implementation)	There is suficient evidence to show that the implimentation shoud be immediate.
Section 7 (Proposed date of review of guidance)	This is far too distant and should be very much sooner than 2015

Role	Public
Other role	

Location	England
Conflict	no
Notes	I have just seen a television programme where a patient has described his complete change in life since taking abiraterone. In my oppinion this drug should be made widely available. If it saves or lengthens a life it should and must be approved
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If it saves or extends life then it should be made widely available
Section 2 (The technology)	We all no that in time the cost will come down in a free market situation

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 5 (Implementation)	I do not believe enough evidence has been gathered and more awareness of this drug and of the intention not to fund nhs use should be publcised as a patient of 12 months this is the first i know of any drug that could help me in the future and it is wrong for me not to even be given the chance of survival the same criteria for extending lives could be applied to many other circumstances of disease or accident where cost effectivness is applied for instance is the guilty party in a motor accident not worth the price of emergency and subsequent treatment it is morally wrong to deny life without certainty about a drug until more positive evidence is proven

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a prostate cancer sufferer I cannot understand the decision to decline a recommendation for this drug. Although not presently at the stage where it would be prescribed it was a light at the end of the tunnel should it be needed if my radiotherapy and hormone therapy prove unsuccessful
Section 2 (The technology)	Although some of the side effects are undesirable they sure as hell beat death from cancer
Section 3 (The manufacturer's submission)	Whilst I am not technically competent to comment on the detail in the report it seems to me to be very much financially based without taking into consideration two factors-the value to the individual and society of life extension and the permanent value to those condemned to death where abiraterone provides complete relief and control
Section 4 (Consideration of the evidence)	The decision leaves prostate cancer as the "poor relative". One can only wonder whether it would have been approved if it had been effective against breast cancer aka Tamoxifen. The case for permanent remission following abiraterone treatment appears to have been ignored.
Section 5 (Implementation)	None
Section 6 (Related NICE guidance)	None
Section 7 (Proposed date of review of guidance)	Not an unreasonable timescale

Role	Public

Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agree with Point 1.2 - the treatment should be made available and the clinician and patient should decide when it is appropriate to stop.
Section 2 (The technology)	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side effects * No alternative treatments available, the alternative is death.
Section 4 (Consideration of the evidence)	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side effects * No alternative treatments available, the alternative is death.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I wish to add my strong support for the preliminary recommendation as at 1.2.
Section 4 (Consideration of the evidence)	I support the findings as outlined in 4.3: Important benefits of abiraterone, as outlined by the patient experts. The importance of these benefits to the patients and in a wider sense, to their families is clear, enabling extension of life, reduction in pain and resumption in many cases of previously enjoyed mobility. In my opinion, this is worth the additional costs involved.
Section 5 (Implementation)	Useful framework, to enable lay analysis.
Section 6 (Related NICE guidance)	No other comment.
Section 7 (Proposed date of review of guidance)	No other comment here.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 7	I think it is scandalous that you are potentially condemning 10,000 men a year,who

(Proposed date of review of guidance)	contract prostrate cancer,to death if you restrict the use of abiraterone.

Role	Carer
Other role	
Location	England
Conflict	no
Notes	£3000 a month to keep a patient at home living a normal life is a very small price to pay.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	No sufferer should be denied this treatment
Section 4 (Consideration of the evidence)	The cost of Abiraterone is not too high for the quality of life it can provide

Role	Public
Other role	
Location	England
Conflict	no
Notes	After watching Hugh Gunn on east midlands today I felt compelled to support the camaign for this drug to be made available to all prostrate cancer suffers. It should not be limited to two years only unless a more superior option becomes available. Scientist work hard to find treatments for all kinds of illnesses and when something comes along that has a chance of curing or helping those suffering a better quality of life then the goverment should fund them and make them widely available to all patients who need them. When you see some very expensive and less worthy causes they fund it makes my blood boil to see the lack of funding for treatments. Yours sincerely
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have watched the evening news which states the benefits of Abiraterone I feel that this drug should be made widely available on the NHS with no restrictions on time at least until a more superior drug becomes available scientists work hard to find treatments, what is the point if they are not funded and made available to help people regain a better quality of life or better still be healed from there illness please make this drug available to those who are in need of it.
Section 2 (The technology)	As stated NICE and other drug companys work hard to treat a variety of illnesses the Gov need to make funds available on something that has been proven to work so effectively
Section 3 (The manufacturer's submission)	I am sure the tests and results can show conflicting and maybe seemingly almost impossible results but as a lay person surely there can be other underlying factors for some results shown.
Section 4 (Consideration of the evidence)	What price would you put on your life or that of a loved one. What price would David Cammeron put on his life or that of his own family?

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Being a prostate cancer patient is a long hard road and this drug helps to ease the way I am not a medical man but I know what works please consider my and more importantly any future suffers in the future

Role	other

Other role	friend of patient with prostrate cancer
Location	England
Conflict	no
Notes	I feel this drug should be available to all patients that it will benefit reardless of cost if this saves a life, I have lost a sister to cancer and experienced the devastation this loss impacts on a family anything that can save a life should be available!! please please please approve this drug for general use, thank you in anticipation.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Itis vital that patients receiving abiraterone shuld have the option t continue treatment until and ONLY until their clinician considers it appropriate to stop
Section 2 (The technology)	It is imperative that the Department of Health takes advantage of the discount scheme offered by the manufacturer and should encourage this scheme to continue or obtain a permanent discount for all patients who have paid into the NHS scheme for many many years.
Section 3 (The manufacturer's submission)	The manufacturers submission on the effectiveness and cost relation is convincing
Section 4 (Consideration of the evidence)	The Committee should study individual cases where lives have been transformed within a short time as I witnessed on a local TV programme this evening. Monetary considerations should not even be part of the equation.
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	April 2015 is too late a date

Role	Patient
Other role	
Location	England
Conflict	no
Notes	It irreversibly blocks cytochrome P17 (an enzyme involved in the production of testosterone), thereby stopping androgen synthesis in the adrenals, prostate and the tumour. If this works then continue to use it - the resultant clinical experience will result in more understanding of HOW the Prostate can be dis-armed. I am a watchful waiting patient who has a major interest in having a POSITIVE PLAN B/C - it shines a light into my future. GOOD NEWS

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Comment on 1.1 There are many cases reported where abiraterone prolongs life for years in this case
Section 2 (The technology)	The cost of £2930 should not be considered as a burden to the NHS. This cost is

	still very much below the cost of drugs given for breast cancer patients. Therefore any decision based on cost discriminates on gender cancer treatment.
Section 3 (The manufacturer's submission)	There are many reported cases of abiraterone prolonging life for much longer than the Kaplan Meir curve predicts. This method can should not be used to make such critical decisions without consulting actual reported cases also.
Section 4 (Consideration of the evidence)	A comparison should be made between the drugs prescribed for Breast cancer and those prescribed and available for Prostate Cancer. Men should not be desciminated against, as this jugement suggests.
Section 5 (Implementation)	The interim decision not to prescribe abiraterone in the UK is completely wrong. This drug is widely available throughout the rest of World and also is being made available to patients in Wales. The drug, originally developed in Leicester, has been proven to extend life by many years in some cases and is more effective, and probably less expensive than the chemotherapy given to those with advanced prostate cancer.I do not believe any decision taken not to prescribe this drug should be made on the basis of cost. It cannot be right when an drug invented and developed in the UK can be withheld when the clinical benefits are known world wide. I would also make the point that this decision if challenged in the courts would be upheld, not only on human rights grounds,but as it will be available in Wales this would amount to descrimination. Also if a comparison is made with the drug treatments available for Breast Cancer, which is a cancer which has synergy with prostate cancer,then to deny men this drug,is wrong and amounts to disadvantaging male cancer patients. Men are very much disadvantaged in cancer research already if the comparison is made to the amount of money spent on research into breast cancer, to that spent on prostate cancer. I would urge that this interim decision is reversed immediately and arbirtarone be made widely available for clinical prescription as soon as possible.
Section 7 (Proposed date of review of guidance)	No to review this guidance until 2015 is condeming men to death, when the evidence supporting the effectiveness of this drug is overwhelming. A review is not necessary. This drug should be approved immediately.

Role	other
Other role	Retired member of Healthcare Industry.
Location	England
Conflict	no
Notes	Although for approx. 20 years I worked with Medical Infusion Technology, I also worked seperately in the area of Prostate Cancer.At one stage I was a Clinical Research Associate for trials of Prostate Cancer chemotherapy.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Section 1.2 is to be prefered
Section 2 (The technology)	As castration has always been accompanied by the risk of androgen production in the adrenals,the aproach listed in 2.1 is entirely logical.The cost of treatment must always be balanced against the cost of palliative care,"end-stage" hospice or hospital care and "social cost" in any family and/or community.The recent reports of very quick pain relief after starting this therapy also have a real "cost saving" for the individual patient.
Section 3 (The manufacturer's submission)	The reported increase in survival times with control of metastasis (and concommitent reduction in bone pain ?) must be significant, if only on a humanitarian basis.They must also have financial implications which can be used to off-set therapy costs.
Section 4 (Consideration of the	I would repeat the comments made re Section 3. Further, the ability of the patient to

evidence)	take the therapy by mouth (and therefore potentially at home) has enormous benefits, both financial and psychological,to many patients.Again ,the costing of "home administration" versus hospitalised administration of the therapy, must be taken into account.
Section 5 (Implementation)	none.
Section 6 (Related NICE guidance)	None.
Section 7 (Proposed date of review of guidance)	My hope would be that at the forthcoming review date, a recommendation to continue to make this therapy available via the N.H.S.,to the appropriate patient group,is reached.

Role	Public
Other role	
Location	England
Conflict	no
Notes	I believe the cost, effectiveness and speed with which this drug appears to have proved its efficacy thus far would warrant further invetigation with a view to approving its use.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a prostate cancer patient currently having hormone treatment. I hope for my future treatment that if I require medication to continue with my good quality of life that the option of taking abiraterone will be available to me and to all the other men that I know in the same situation as me.
Section 2 (The technology)	I understand the cost will be less to the DoH I feel this must make the treatment affordable and therefore available to those of us in need.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My dad has just been told he has prostate cancer, I want him to have the best chance possible for survival.
Section 2 (The technology)	It is hard to put a price on someones life, to me my dad is priceless.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I have taken Arbiterone for approximately 8 weeks now and it has made a vast difference to my health and wellbeing. Chemotherapy had stopped working and my PSA was increasing weekly. The PSA has now reduced drastically and I feel better than I have for a long time. I am one of the lucky ones given the chance to take this drug and am extremely grateful. My quality of life has improved immeasurably. Please do not deny either myself or other prostate cancer sufferers the chance of taking this drug. Money is not a substitute for life.

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Having been on Abiraterone for 2 months I would be devasted to stop taking it as it has proved a lifeline to me. I feel better now than I have for a considerable time. The drug works and should be continued for as long as I need it.
Section 2 (The technology)	It may have side effects but I have not suffered any myself. The cost is high but the NHS would not pay £2930 per month. It has to be worth whatever it costs if it prolongs a normal active life as is the case with myself.
Section 3 (The manufacturer's submission)	Still better on Abirterone than not
Section 4 (Consideration of the evidence)	I can only comment on my reaction to Abirterone and that is definitely positive on all fronts.
Section 5 (Implementation)	Cost cannot be the main issue. The benefits are immeasurable as is life itself.
Section 6 (Related NICE guidance)	All developments are important.
Section 7 (Proposed date of review of guidance)	This should be reviewed if guidance is needed at an earlier date

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I wish to support 1.2People currently receiving abiraterone in combination with prednisone or prednisolone for the treatment of castration-resistant prostate cancer that has progressed on or after a docetaxel-containing regimen should have the option to continue treatment until they and their clinician consider it appropriate to stop.
Section 2 (The technology)	support 2.3The Department of Health considered that this patient access scheme does not constitute an excessive administrative burden on the NHS. The manufacturer has agreed that the patient access scheme will remain in place until any review of this NICE technology appraisal guidance is published.
Section 3 (The manufacturer's submission)	support use of abiraterone where appropriate to extend life expectancy of prostate cancer patients
Section 5 (Implementation)	support use of abiraterone where appropriate to extend life expectancy of prostate cancer patients

Role	other
Other role	Son of patient
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	On behalf of my father who has limited access to the Internet: whilst the cost of this drug is high compared to others available it does have merit in the form of its proven effectiveness, rather than removing this drug from use entirely would it not be more cost effective in the long term (considering the cost of radio and chemotherapy which in many cases are the alternatives) to use this drug as a "last resort" in cases where other drugs have failed or are starting to fail?

Role	Patient
Other role	
Location	England
Conflict	no

Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone has been prescribed to me since April 2011 (date now 22/2/2012) It has given me a complete new lease of life. Before Abiraterone, I was in a huge amount of pain and quite honestly had no quality of life at all. The drug has completely and utterly changed my quality of life.
Section 2 (The technology)	I believe i must be part of the Patient access scheme, Leicester Royal Infirmary, referred by Prof Simmons. The £2930 is a considerable amount of money, although the quality of life it has given me far outweighs the cost.
Section 5 (Implementation)	I may be repeating the text from earlier, but I cannot ask strongly enough that other individuals should benefit from this drug like I have, otherwise 10,000 people per year will not receive the benefit I have. I understand it will not work for all, but surely the results of a certain percentage should encourage NICE to implement this across the country.

Role	Public
Other role	
Location	England
Conflict	no
Notes	N/A
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe it is everyones right to life and that you should continue to provide this drug.
Section 2 (The technology)	I cannot understand how the makers can justify the cost.
Section 3 (The manufacturer's submission)	A lot of gobbledegok to blind people with science
Section 4 (Consideration of the evidence)	As far as I am concerned even if this drug saves only 50% of men. It has done far more than other drugs have succeeded in doing as as such men with prostate cancer should be given the chance to have it.
Section 5 (Implementation)	N/a
Section 6 (Related NICE guidance)	N/a

Role	Public
Other role	
Location	England
Conflict	no
Notes	i think that every available drug that is on the market should remain available to those who are helped by it, i just wished my father who died from prostrate cancer over 15yrs ago could have had the opportunity to try this drug, as long as quite a lot of people are being helped then others should be given the chance as well. regards lesley franks
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	please allow people who are being helped by this drug to continue with the use and to let anyone else that has prostrate cancer to be given to them to hopefully help them. i wish it had of been available for my dad who died from prostrate cancer over 16 yrs ago. i agree that it should stop for individual patients if it dosnt work.
Section 2 (The technology)	the discount should remain in place, if it only helps a few if it your family that is involved we would all want it to remain.
Section 3 (The manufacturer's submission)	this all goes over my head too many abrevated words i do not understand, but my words still remain the same, give anyone a chance of survival they deserve it.
Section 4 (Consideration of the evidence)	my thoughts remain the same, give everyone a chance, because what we are saying is that if you are rich you can buy what you need to make the rest of your life more comfortable and if your not so rich tough.

Section 5 (Implementation)	i think it needs to remain longer and say 12 months not 3, if it helps 10 out of 100 mens live a better live this is good, men are not good a sticking up for them selfs and need help from us women
Section 6 (Related NICE guidance)	this is all a bit jargony for most people and not easily understood.
Section 7 (Proposed date of review of guidance)	yes that sounds good as long as nothing changes in the meantime and men still can get this drug if it helps them

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	22nd February 2012 National Institute for Health and Clinical Excellence MidCity Place 71 High Holborn London WC1V 6NA Comments from Thames Valley Cancer Network (TVCN) Urology TSSG regarding: ABIRATARONE for Castrate Resistant Metastatic Prostate Cancer patients previously treated with DOCETAXEL containing REGIMEN. The TVCN Urology TSSG was disappointed with the committees decision not to approve Abiraterone acetate for use in CRPC following prior chemotherapy. There is global consensus in the Uro-Oncology community that this agent is the first of a class of drugs which represent a paradigm shift in the management of advanced Prostate Cancer. The overall survival advantage of 3-4 months in CRPC patients who have failed Docetaxel offered by Abiraterone represents a major breakthrough in prostate cancer treatment. In response to the preliminary report we would like to make the following comments to NICE: 1. The Committee has accepted the proven efficacy and safety of Abiraterone. continued below...
Section 5 (Implementation)	2. We would disagree with the Committees assumption that it was not appropriate to restrict the population considered in the basic analysis to the sub group failing one prior chemotherapy treatment. Urologists and Oncologists in the United Kingdom would argue that this assumption is correct and accurately reflects the population of CRPC patients. Currently patients would rarely receive more than one chemotherapy. The Expert Review Group also agreed with this in their report. 3. The Committee agrees that the criteria related to short life expectancy and extension of life were met, but they argued that Abiratarone was not licensed for a small population. The definition of what constitutes a small population is debatable and clinicians on the ground dealing with these patients would argue that the improvement in overall survival should be the overall guiding principle. Such survival advantage is unprecedented in these patients and therefore arguing on

	hypothetical grounds about numbers of patients is irrelevant. Continued below...
Section 6 (Related NICE guidance)	4. It is very disappointing that both Abiratarone and the chemotherapy agent Cabazitaxel have been rejected for use in the NHS by NICE in recent weeks, despite both offering patients with castrate-resistant prostate cancer improvement in survival over currently available treatments. This will therefore limit patient choice and that of healthcare professionals to offer the best available treatments to NHS patients. Signed on behalf of the TVCN Urology TSSG,

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone should be universally available to all patients on the NHS.
Section 2 (The technology)	Cost should not be the prime consideration when considering use of this drug.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	Abiraterone is the best alternative for a life prolonging regime, with fewer side effects and better patient outcomes
Section 5 (Implementation)	Nice should recommend abiraterone for use on the NHS.
Section 6 (Related NICE guidance)	Abiraterone should be the drug of choice
Section 7 (Proposed date of review of guidance)	This advice should be reviewed asap

Role	Patient
Other role	
Location	England
Conflict	no
Notes	we all should have the best treatment avaiable , rich or poor
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	all who are suitable should have treatment
Section 2 (The technology)	given time and more people taking the drug costs will come down
Section 3 (The manufacturer's submission)	saving could be found
Section 4 (Consideration of the evidence)	treatment should be available for all , rich or poor
Section 5 (Implementation)	think again , it`s peoples lives

Role	Public
Other role	

Location	England
Conflict	no
Notes	As someone who has just undegone tests for suspected prostate cancer I was very concerned to hear toaday that funding for abiraterone is to be withdrawn. Compared to the way in which the NHS wastes money in my opinion on many much less deserving projects this decision needs to be urgently re -assesed as it is going to condemn many sufferers to an early death from what I can see! Please, please, please do not withdraw this funding as prostate cancer sufferers deserve every possible chance of treatment available, personally Im already scared and this just made me feel much worse when I heard the news today. Regards
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	disagree
Section 2 (The technology)	dont understand
Section 3 (The manufacturer's submission)	agree
Section 4 (Consideration of the evidence)	sufferers have found the drug extremely beneficial thats what counts
Section 5 (Implementation)	ok
Section 6 (Related NICE guidance)	dont agree
Section 7 (Proposed date of review of guidance)	too late hundreds of men will be dead by then!!!!

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Undoubtedly paitents receiving abiraterone in combination with predisolone after a docetaxel regime should have the option to continue treatment
Section 2 (The technology)	Given that the NHS is happy to fund the removal of PIP breast implants which originally were inserted largely for cosmetic reasons, usually paid for by the patient to clinics now washing their hands of their responsibilities, the cost of abiterone is a small price to pay

Role	NHS Professional
Other role	Public
Location	England
Conflict	no
Notes	I think that rather than saying this drug can only be funded for two years Nice should look at new clinical trials to prove the value of this drug. We treat people who have never contributed anything to society both foreign and domestic yet we are willing to condemn ten thousand men a year because we would rather waste billions reforming the NHS and paying for treatments which should be done in the private sector eg pectus excavatum, gastric bypass surgery, TAVis
Comments on individual sections of the ACD:	
Section 1	I agree with both statements

(Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	I think that if the drug is used in sufficient patients the Government could negotiate a lower price for the drug after the 3 year period has expired
Section 3 (The manufacturer's submission)	No comment
Section 4 (Consideration of the evidence)	No comment
Section 5 (Implementation)	
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	I agree

Role	Public
Other role	
Location	England
Conflict	no
Notes	My father had bhp
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I understand this drug can be life enhancing and life prolonging for those with this type of cancer if this were a drug for women with cancer, no doubt it would be approved.
Section 2 (The technology)	How much is a single life worth?
Section 3 (The manufacturer's submission)	This drug obviously prolongs life - authorise it immediately!
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	NICE must recommend use of this life-prolonging drug.
Section 6 (Related NICE guidance)	
Section 7 (Proposed date of review of guidance)	too long: review needed in 12 months

Role	Local government professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	This evidence is comPelling support for this drug.
Section 4 (Consideration of the evidence)	This case should be reconsidered for wider use on the basis of the quality of life outcomes experienced by users.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am 72 years of age and have been fighting advanced prostate cancer for three years. I have had eight chemotherapy sessions since last July, another two

	sessions to go. And what then? After having worked and paid tax to the government for over half a century, are you telling me to go away and die because I am not worth the cost of this medicine?

Role	Carer
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As one of the biggest killers of men in this country it would be totally obscene to deny them this treatment, to the point of being discriminatory, bearing in mind the vast amount of money spent on breast cancer & ovarian cancer, screening and treatment.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I agree entirely. This is an important treatment that benefits from this drug
Section 2 (The technology)	Excellent treatment
Section 6 (Related NICE guidance)	Dont change a drug that works

Role	Public
Other role	
Location	England
Conflict	no
Notes	my father died from this 3 years ago. had this been available who knows? anything that gives some increased chance of cure or halting of this type of cancer should be made available. remember people have spent a lifetime investing via taxes and ni contributions and are entitled to the best we can offer, also you are getting older and more susceptible, if available would you want it?

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I wish to register my deep concern that the committee, which has already concluded that there is evidence that Abiraterone is an effective second line treatment for castration resistant metastatic prostate cancer, is now stating that the use of this life extending treatment should be withdrawn. The fact that this treatment is administered in the patients home should carry a considerable weight as the costs of in hospital treatments are therefore substantially reduced - thus reducing the overall costs of the Abiraterone overall. The benefits to the patients and their families cannot and should not be underestimated. Please reconsider the decision to withdraw this treatment. Thank You.

Role	Patient
Other role	
Location	Wales
Conflict	no

Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The final appraisal recommendation of the All Wales Medicines Strategy Group (advice no: 0612 February 2012 has been to recommend Abiraterone with prednisone or prednisolone in circumstances where the approved Wales Patient scheme for access to medicines is utilised, should be made available across the U.K.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	iT IS UNFORTUNATE THAT, DESPITE THE COMMITTEES CONCLUSIONS WITHIN SECTION 4 that price costs are at the heart of the committees refusal to endorse the adoption.
Section 4 (Consideration of the evidence)	The Appraisal committees own conclusions as at 4.2, 4.3, 4.11 to 4.16 and 4.20 stated that Arbiraterone was an effective second-line treatment for castration-resistant prostate cancer, and that median survival was statistically significantly longer in the Abiraterone group of the trial.
Section 5 (Implementation)	
Section 6 (Related NICE guidance)	The overall conclusion is that financial considerations were brought to bear on this interim decision. This is difficult to accept in the wider field of Health, where upwards of 40,000 women have been assured that costs in relation to the PIP breast implant scandal will be met by the NHS. tHE OVERWHELMING MAJORITY OF THAT GROUOP WOULD HAVE UNDERTAKEN THIS SURGERY BY CHOICE, WHICH WOULD CERTINLY NOT BE THE CASWE FOR PROSTATE CANCER SUFFERERS. wHERE IS THE JUSTICE IN THIS CASE.
Section 7 (Proposed date of review of guidance)	Review date is not required - ACT NOW to remedy this situation.

Role	Public
Other role	Male
Location	England
Conflict	no
Notes	A similar number of men die from prostate cancer as do women from breast cancer, yet the publicity, research, and money spent on treatment disproportionately favours women - this should be addressed. A first line of male treatment involves effectively, chemical castration, with all that implies in terms of male self-image, erectile disfunction, etc. It is quite simply a disgrace it produces a change in fundamental personality which the medical profession would never dare offer women for their problems. Castration is a cheap and nasty remedy only adopted by desperate men trying to hang onto their threatened lives. Abiraterone and Cabazitaxel have been fully tested and adopted in the USA, so why is NICE insisting on re-inventing the wheel and then concluding these drugs are not appropriate? Is life less precious in the UK (ignoring Scotland)and not worth the cost? Why is NICEs remit not expanded to include the ability to negotiate drug prices and other monetary arrangements? For example, some drugs used for multiple myeloma are only effectively paid for if the patient is shown to actually benefit from them. This of course takes into account not only the drug manufactures efficacy claims, but also the peculiar response of individual patients.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It would be unreasonable to do otherwise
Section 2 (The technology)	And can the manufacturer be persuaded to put his money where his mouth is? Ie only charge for the drug with patients with whom it is effective?
Section 3 (The manufacturer's	It may be convenient, but is it good practice to rely upon the manufacturers

submission)	literature survey? What about the literature studies used in the USA decision - or does NICE believe manufacture influence in the USA work to be suspect?
Section 4 (Consideration of the evidence)	I consider the Committee must explain when it comes to different conclusions from authorising bodies in the USA and Europe. And any political pressure upon the Committee from current attempts to reduce the NHS costs should be clearly recognised and made public.
Section 5 (Implementation)	Has much changed?
Section 6 (Related NICE guidance)	I thought NICE had already rejected Cabazitaxel!
Section 7 (Proposed date of review of guidance)	No comment

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The great myth that needs debunked here is that drugs like this only buy a few months. I have friends alive many years after taking Abiraterone. Another myth about prostate cancer is that it only affects elderly men who are going to die anyway. There are many patients younger than 50 years of age at diagnosis. This is NOT just an old mans disease and these drugs are NOT for short term gain! Despite having a diagnosis and death rate similar to breast cancer, the NHS spends up to a fifth of the money on prostate cancer that it does on breast cancer.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	Generous public donations to Cancer Research UK and other organisations paid for the initial development of the drug and it is disappointing that the drugs manufacturer couldnt offer NICE a price they could agree on. NICE should take another look at the way they have reviewed the cost-effectiveness of Abiraterone. It is hoped this, and a revised offer from the manufacturer, would result in the drug being available to patients who desperately need it.
Section 4 (Consideration of the evidence)	NICE has used the wrong criteria to judge its cost effectiveness. If NICE looked carefully at how many men would benefit, the overall cost could be more manageable than the initial calculations indicate. Trials show men taking Abiraterone and a steroid survived for nearly 15 months, while men given steroid treatment and a ?dummy? pill lived for 11 months on average. But some patients live far longer than expected, including Britons who have survived on the drug for more than four years after developing advanced disease. The drug also eased pain for twice as many men in the trials.

Role	Carer
Other role	Retired General Practice Nurse
Location	England
Conflict	no
Notes	My husband was told 2-3yrs ago about this drug that would possibly be available for use when all other options had been tried and eventually failed.He has suffered with this terrible disease for 11yrs. Those years have been bad news after bad news with eventual failure of every treatment and very poor quality of life latterly.His bone mets pain pulled him down even further following chemo toxicity last year and also constant nausea post chemo(not during)that was only responsive to dexamethasone. When abiraterone was commenced after Christmas his bone pain and nausea

	disappeared within 10 DAYS and he has been a different person since. We have recently been away for a few nights and are planning a fortnight away in the summer. It is wonderful to have him back for this special period of time. He has walked his daughter down the aisle,enjoyed a new grand daughter,seen another grandchild on scan and we pray that he will be with us to enjoy her arrival in August. Please remember all the researchers who have achieved so much for the treatment of advanced prostate cancer and its cruel progress and the tremendous excitement this drug has generated, not only for the patient, and medical profession, but all those who have walked the journey with the patient. I plead hard for this decision to be overuled. This amazing drug MUST be allowed to be used.Herceptin is used now, under womens pressure to overturn NICES initial decision. Please remember men are not so health-aware as women and therefore will not be so vocal over this drug. I am passionately asking you to reconsider this amazing drug, that has given my husband some extra time with a hugely improved quality of life, for use following chemotherapy. Many thousands of men will benefit and who knows what it may lead to in futher research for prostate cancer, an insidious, sapping, terrible disease.

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	As stated the Committee has concluded that the evidence demonstrates that abiraterone is an effective secondline treatment for castration resistant metastatic prostate cancer. It improves overall survival, progression free survival, and relieves symptoms (pain, functional deterioration, fatigue).
Section 4 (Consideration of the evidence)	4.2 Is the data that 20-30% of prostate cancer patients with PD post docetaxel receive mitoxantrone recent? With no survival benefit, and only 38% of patients experiencing reduced pain, the use of this agent for analgesia is not widespread in view of its side effects: 1% febrile neutropenia 29% n & v 24% alopecia. Clinical specialists stated it is unlikely abiraterone will be delivered to patients with an ECOG PS of 2 (in the COU-AA-301 study only 10% of patients had an ECOG of 2). Section 4.4 states that participants in the COU-AA-301 study were likely to be healthier than those who would receive abiraterone in the UK. This is inconsistent with the previous statement as the exclusion criteria for the trial would also apply in daily clinical practice. 4.4: The mitoxantrone arm of TROPIC cannot be compared to the abiraterone arm of COU-AA-301. However in the 1996 Tannock study (JCO14:1756-64) in chemotherapy naÃ¯ve patients, mitoxantrone (+P) failed to show a survival benefit over prednisolone alone. The COU-AA-301 study (previous docetaxel) did show a survival benefit for abiraterone (+P) over prednisolone alone. 4.5 The Committee considered the different measures of PFS, a secondary end-point. Biochemical (PSA) PFS is the standard method for assessing this in prostate cancer, as radiological progression is difficult to assess, and time to treatment discontinuation is prone to the confounding factors mentioned in the document.

Role	other
Other role	Daughter of patient
Location	Wales
Conflict	no

Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If there is no other option of any further treatment is it not unfair to withold a drug that could potentially extend life?
Section 4 (Consideration of the evidence)	As already demonstrated by the evidence given men would benefit from a better quality of life with less pain and improved symptoms of fatigue.This could therefore reduce the number of patients requring analgesia and hospital admission therefore saving money for the NHS.The fact that the drug can be taken orally compared to Mitoxantrone which would need to be adminstered in a hospital setting therefor costing the NHS more money,needs to be considered.Taking an oral alternative not only provides the patient with independance and dignity it would take some burden off the NHS. The treatment itself appears to be well tolerated with limited side effects which is beneficial to the patient in improving the quality of life.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Many men suffer from metastatic prostate cancer because diagnosis was late. It is a great shock to learn it is incurable and very necessary for the long-term health and quality of life of the patient to know that it is not a death sentence, as hormone treatments (eg Zoladex, which is the treatment I receive) can keep it at bay for many years. However, knowing this is a ticking time-bomb with very poor prognosis when the cancer becomes resistant has a deep psychological effect and the availability of abiraterone as an option for when this happens is a life-enhancer equally as significant as the extension of life it gives. This gives the cost of the treatment a different and wider perspective. I ask NICE to reconsider its recommendations in the light of the value for money to patients, and therefore the NHS, that abiraterone provides in the longer-term as well.

Role	Public
Other role	
Location	England
Conflict	no
Notes	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects * No alternative treatments available, the alternative is death.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects

	* No alternative treatments available, the alternative is death.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a prostate cancer patient who has come to the end of conventional treatment, and my consultant recomends that Abiraterone would be of benefit to me.Whilst I have to be guided by him it seems hard that I that I am denied a drug that could prolong my life.My quality of life is still good for which I am very grateful to the NHS but it would seem that Abiraterone is now my only hope.I can only hope that you come to a positive decision. Thank you - John Winterton.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel that if a consutant with his or her experience recomends that the treatment treatmentwould be of benefit then it should be available for use.
Section 2 (The technology)	I am hoping to qualify as I apparently meet the criteria but this is not yet confirmed.
Section 3 (The manufacturer's submission)	I have read and must accept their conclusions.
Section 4 (Consideration of the evidence)	It would seem that their is a sound case for using Abiraterone to extend life where suitable conditions apply
Section 5 (Implementation)	One accepts that it is not cheap but could it be that with greater use the the cost would come down.The decision to use or not should always be decided by the patients consultant.
Section 6 (Related NICE guidance)	Whilst NICE always as a balancing role to play the evidence is always being added to as time passes
Section 7 (Proposed date of review of guidance)	I suppose by that date a lot more evidence will be available though its unlikely I shall be about it to see it

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I have no experience of medical analyses, but a grounding in statistics. Fellow patients have highlighted to me the great personal benefit of using arbiraterone. From what I understand, the conclusions are drawn mainly from the QALY and ICER measures, and their interactions. I would find it more beneficial to have a direct reference to their formulation, including the relevant weightings.

Role	other
Other role	Patients relative
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.)

	* Very few side affects * No alternative treatments available, the alternative is death.

Role	Patient
Other role	Clinical Trial Volunteer
Location	N Ireland
Conflict	no
Notes	I have to say I am appalled at the (provisional) decision by NICE not to approve the use of Abiraterone on the NHS. I was diagnosed with advanced metastatic prostate cancer at the age of 51. To date, I have managed to survive fours years on conventional HT treatments but I know my luck wont last forever. For men like me, drugs like Abiraterone (a British invention) provide hope. I know men on the drug (from clinical trials) who have survived for several years and are still going strong. It does NOT just buy you a few months and thats all. Some of my friends have moved on to other drugs (again via trials) and this is what I hope to do. What is the point of men like me volunteering for these trials if NICE wont agree to fund the drugs, especially when the medical evidence is overwhelming? True, the drug companies need to be more reasonable but there is nothing more annoying that seeing great medical advances like Abiraterone being deployed across the EU (and the rest of the World in general) whilst being denied to men in the UK. Its even more upsetting to men like me who live in N.Ireland and who have no access to the Cancer Drugs Fund as a possible alternative. Prostate cancer has almost the same diagnosis and death rate as breast cancer but yet it would seem that men are very much second best when it comes to NHS funding. Yours Angrily
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agree
Section 2 (The technology)	Cost sounds reasonable but without disclosing discount its hard to evaluate
Section 3 (The manufacturer's submission)	Major medical advance of which the UK can be proud (but not if we dont approve it on the NHS)

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Please reconsider your decision not to recommend abiraterone on the following grounds: There is potential to increase life by years. On the 9 month trial, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. The ability to help men to keep in employment and not have to claim benefits because of ill heath Greatly increased quality of life with much reduced pain Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) Very few side effects There are no alternative treatments available after all the chemotherapy options have been exercised. There are drugs available for other conditions so why should men be denied this one option? This is the one life-line left for men with this condition.

Role	other
Other role	Member of Parliament
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have received representations from constituents who cannot understand why Abiraterone has been approved for use in Wales but is not recommended to be approved for use in England. They have asked that I make such a representation on their behalf and request that NICEs decision is reviewed in light of this development.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Government should ensure that sufficient funding is raised from taxes to enable drug to be prescribe no matter how expensive. Although the success of medication cannot be guaranteed an attempt to preserve life is paramount beyond everything else. No further comments should be necessary.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Please allow this drug to be licensed as I have afreind who is receiving it and it has improved his life beyond expectations How can you put a cost onsomeone,s life?

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Refusal to supply abiraterone is condemning advanced sufferers of Prostate Cancer the opportuniy of extended life,or final life as comfortable and pain-free as is possible. Where is your compassion?

Role	Public
Other role	
Location	England
Conflict	no
Notes	I was unsure where to write my general submissions so have included them here. I am a relative of a patient with prostate cancer. He receives this drug and prior to getting it, his PSA was doubling every month. His health was failing dramatically. As a result of being prescribed Abiraterone he is now fit and enjoying life. There is no other drug available for men with this stage of prostate cancer so a rejection of Abiraterone is quite literally a death sentence. In terms of funding, my understanding is that methadone costs £3,000 per month. A huge number of people receive methadone (which is not a life saving treatment) with no funding difficulties whatsoever. Why should men who will die without this drug be treated any differently? I would also make the following specific comments:

	- Abiraterone has the potential to increase life by years. Not just 4 months. The 4 month figure appears because the trial ran only for 9 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * This drug doesnt just keep men clinging to life, it gives them back a good quality of life. Potentially, with the ability to keep them in employment and not having to claim benefits because of ill heath * Abiraterone offers a greatly increased quality of life with much reduced pain * It is very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * It has very few side affects * No alternative treatments are available, the alternative is death.

Role	Public
Other role	
Location	Wales
Conflict	no
Notes	My best friend suffers from Prostate Cancer and is currently being prescribed Abiraterone to great effect
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I disagree with the Committees recommendation and hope that it will be overturned
Section 2 (The technology)	I note that you highlight adverse reactions but not the enormous positive reactions
Section 3 (The manufacturer's submission)	I find ironic that a treatment developed in the UK should be denied to UK residents. What a negative message to send to the manufacturer. Why should they bother to work on such developments in the future?
Section 4 (Consideration of the evidence)	I do not believe in prolonging life for its own sake - especially when the quality of life is extremely poor. However I have seen with my own eyes the immensely positive effect of this medication on a man who would otherwise be in a very bad way. I believe the committee is grossly underestimating the positive effect of the treatment on people who would otherwise literally have nothing left to live for.More work must be done in this area to better inform your final decision. If the decision is still negative then at the very least there should be a recommendation that patients who already receive the treatment should be allowed to continue with it until their lives come to an end. Any other course of action would be an act of inhuman cruelty
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No comment

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 deeply disappointed to learn of the rejection by NICE of Abiraterone. The drug seems to have the potential to increase life by years rather than the minimum of 4 months shown in the limited trials. The reduction of pain associated with the use of Abiraterone also ensures a much better quality of life.

	It seems to me that men with prostate cancer get a very raw deal. There is no formal awareness programme, let alone a screening programme. GPs often expect symptoms before allowing men to have a PSA test ? when, in fact, men frequently don?t show any symptoms until the cancer has metastasised. The bottom line is that a man is very fortunate to be diagnosed with localised prostate cancer which can be cured. He is more likely to be diagnosed with metastatic cancer. And now NICE is intent on failing those same men at the very end of their lives. I very much hope NICE can find a way to make Abiraterone available to men with terminal prostate cancer.

Role	Carer
Other role	Secretary
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Re-assess criteria re the number of men requiring Abiraterone (Ab) - no. will reduce as awareness/early diagnosis increases Reconsider ?average? re Ab effectiveness, some men will live 4 months, others much more Liaise with Janssen re costs Cost effectiveness cannot be judged solely on life expectancy, a duty of care means that drugs which increase quality of life (Ab effectively reduces pain) should be available to all patients regardless of gender, race, age, ability to pay (NICE?s recommendation perpetuates gender (male only disease), race (3 x more African Caribbean than White men have PC hence more African Caribbean than White men will require access to Ab) & age discrimination (age at diagnosis is c70). Unless the NHS pays for Ab, men with advanced PC in England/ Wales will face a postcode lottery to access Ab unless they can pay Rejection of PC drugs by NICE, perpetuates the Cinderella perception Funding for PC research is poor compared to female cancers, much of the funding received is from sufferers/families. Fund raising in the current economic climate is difficult, and the risk is if NICE doesn?t recommend PC drugs fundraising will be greatly reduced

Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Studies on abiraterone show that it can prolong the life of men in the final stages of prostate cancer by an average of about 4 months,[1] and improve the quality of their lives. The drug is one of the biggest breakthroughs in the treatment of the disease for many years. It offers men the possibility of extending their lives at a time when there are no other available treatment options, except those that just control the symptoms of the disease. Unless NICE recommends that the costs of abiraterone should be covered by the NHS, men with advanced prostate cancer in England and Wales will face a postcode lottery trying to access this important new medicine. This is unacceptable.

	[1] Abiraterone and Increased Survival in Metastatic Prostate Cancer. Johann S. De Bono, et.al The New England Journal of Medicine Vol 364 No 21 May 2011.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	How can you be so heartless...Arbiraterone cam inprove quality of life,not only extend it...
Section 2 (The technology)	Surely the Dept of Health,should renegotiate costings...I understand the All-Wales Medicine Strategy Group(AWMSG)has approved Abiraterone use,how can the people of England be descrimanated against,if your draft recommendation is confirmed

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Knowing a patient who has not reacted to chemo-therapy treatment, I feel it is essential that Abiraterone be made available as a life prolonging alternative.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 5 (Implementation)	I understand that abiraterone can prolong the life of men in the final stages of prostate cancer and improve the quality of life. My father died from prostate cancer and I have been treated for the same disease. This drug is a big breakthrough in the treatment of a disease that affects thousands of men and I would urge NICE to approve that the costs of the drug be covered by the NHS to offer the possibility of life being extended.

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I support the evidence of clinical patient benefit and improvement in patient QOL. This should be a treatment option for these patients.

Role	other
Other role	Daughter of prostate cancer patient.
Location	England
Conflict	yes
Notes	I work for Cancer Research UK who trialled this drug
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	My father has had every type of treatment available including 8 sessions of chemo. None have stopped his cancer growing , he is now on abariterone with steroids and hormone injections and he is so well His PSA has halved and he has quality of life, he should have the opportunity to continue this treatment s long as it is working.
Section 2 (The technology)	Is there any possibility of the manuifacturing costs being reduced if the deamnd for this drug was higher. As patients continue to be treated wirth this drug and live longer with a good quality of life. Could this evidence be taken into account.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	I am aware that the NHS does not have unlimited funds and that other patients have to be taken into consideration. However, seeing my father so well and enjoying life after a grueling 6 months were a trial drug was his only hope but made him feels so ill he just could noit continue taking it I am overjoyed that he is able to take Abariteron now . The difference in his health (menatal and physical) is incredible. I have my own father back. The thought of this drug not being available to other peoples fathers is so sad. I hope that you will reconsider your decision.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Please see below the advantages of this Prostate Cancer treatment : * The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects * No alternative treatments available, the alternative is death.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Please note the following advantages to this Prostate Cancer treatment : * The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects * No alternative treatments available, the alternative is death.

Role	NHS Professional
Other role	husband age 54 has advanced prostate cancer
Location	England

Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The UK has an unusually high number of young and advsnced/metatstatic men at presentation: this is due to poor prostate cancer awareness, a lack of centrally funded program of awareness and the lack of a screening program. There will be a steady stream of such new cases due to lack of timely diagnosis. Given that, surely it is wrong to deny them appropriate treatment and palliation.
Section 2 (The technology)	This is a novel agent and heralds a new era in prostate cancer management. It has been hailed as a true innovation - and approved for use - is all of the developed world - apart from the UK - where it was developed!
Section 3 (The manufacturer's submission)	Note that clinical trials in the UK rely on the willing participation of UK taxpayers. That they should be denied the use of the drug when they need it is perverse. Why should any UK citizen participate in any clinical trial, and why should any UK citizen contribute to any charities funding such trials given that cancer sufferers in the UK may not benefit from such trials?
Section 4 (Consideration of the evidence)	The number of UK prostate cancer patients receiving chemotherapy remains relatively low - given that eligibility for abiraterone depends on having failed chemotherapy it seems that NICE has hugely overestimated the numbers of men potentially using this drug. This is an orally administered, relatively non toxic drug and does not require the expensive use of chemotherapy unit staff and facilities. Insufficient weight has been given to the improved quality of life and improved palliation on this drug. Bone pain, a major issue for advanced cancer sufferers is improved - this will surely prolong independence. A LOT of patients on abiraterone will live longer than the currently estimated 4 months, some much longer.
Section 5 (Implementation)	It is perplexing to NHS patients in England to see this drug approved by private health insurers in England and by the AWMSG in Wales. Why are English NHS patients being singled out? Do they have to move to Wales?I
Section 6 (Related NICE guidance)	I respect and use NICE guidelines as part of my work. On this occasion, however, I feel you have got it wrong and are failing these men. Please reconsider this unkind decision.

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 NICE has recently issued a draft statement saying they do not recommend that the costs of Abiraterone treatment should be routinely paid for by the NHS in England and Wales. I write in response to this draft statement and would request NICE revisits this decision. My father is a sufferer of a condition that would potentially benefit from Abiraterone. It is a debilitating disease that thousands of men suffer from in silence. It affects not only the sufferer but the wider family. Due to the age of the majority of those who suffer from this disease, their voice is often not heard they are overlooked. Whilst my father has, to date, benefited from hormone therapy (which I know both pains him and has undesirable side effects) I am aware that this treatment option will have a limited time span of effectiveness at which stage alternative treatment options will be required, one of which may have been Abiraterone.

	I am not a scientist or medical professional but my understanding is that there are currently no other non-palliative treatments available on the NHS for men with this type of cancer. Considering the number of men who suffer from this disease and the significant lack of innovative treatment investment it has benefited from comparative to other cancers it seems utterly unfair that NICE is not recommending that this medicine be approved for NHS funding. Men should be able to make an informed decision with the support of their doctor, and via the NHS be offered the choice of a life-extending drug that can allow them a few extra months to spend with family and friends. The recommendation contained within the NICE draft statement will have a hugely negative impact on thousands of men and their families and I?d ask NICE to reconsider their recommendation. It?s simply unjust.

Role	Public
Other role	
Location	England
Conflict	no
Notes	I feel that abiraterone - treatment for men in the final stages of prostate cancer - should be made availalbe on the NHS.Those last few months are very important.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I think it should be available generally
Section 2 (The technology)	The cost is worth it to the patients.
Section 3 (The manufacturer's submission)	I do not understand this but still believe it should be available to those who it offers help to.
Section 4 (Consideration of the evidence)	Drug companies need to reduce the costs of treatment.
Section 5 (Implementation)	The patients needs are paramount.
Section 6 (Related NICE guidance)	make it available as soon as possible
Section 7 (Proposed date of review of guidance)	The consultation date is not soon enough when the treatment is there waiting and people are dying.

Role	Patient
Other role	NHS Retired
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	* The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life.
Section 2 (The technology)	The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.)
Section 3 (The manufacturer's submission)	Very few side affects * No alternative treatments available, the alternative is death.
Section 5 (Implementation)	Very few side affects * No alternative treatments available, the alternative is death.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Please reconsider the decision to deny this drug proven benefit to men with no other help. The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects. * No alternative treatments available, the alternative is death.

Role	Public
Other role	
Location	England
Conflict	no
Notes	As a taxpayer for more than forty years, I find it immoral that men are being denied access to abiraterone in the final weeks & months of their lives, when this could improve their quality of life and even extend it somewhat. This at a time when families have to come to terms with prostate cancer and the reality of premature death.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Unless NICE recommends that the NHS should cover the costs of abiraterone, men with advanced prostate cancer in England and Wales will face a postcode lottery trying to access this important new medicine. This is unacceptable. That NICE consider abiraterone does not meet the criteria because the population of men who would be applicable to receive the treatment is too large misses the point. Surely, the appropriateness of a drug should be based on its effectiveness in treating patients, not how many will require it. I strongly support a reversal of this unfair decision which appears to discriminate against the male population of England & Wales.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone is the only drug at this time which gives prostate cancer patients hope for an extended life. Our friend is only 46 years old and for the last 10 years he has been hoping technology would be able to help him extend his life to see his 4 daughters through school. Not much to wish for but everything to him. The medication would be taken at home, a definite plus, and although there are side

	effects which may occur, please give him the chance of an extended life.

Role	Public
Other role	
Location	Wales
Conflict	no
Notes	We have supported Prostate Cancer Research with an annual contribution through a standing order (Ref.45611/440004) for some 15 years. We feel strongly that this new drug should be available to all.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have insuffiect knowledge to comment in detail
Section 2 (The technology)	I have insuffiect knowledge to comment in detail
Section 3 (The manufacturer's submission)	I have insuffiect knowledge to comment in detail
Section 4 (Consideration of the evidence)	I have insuffiect knowledge to comment in detail
Section 5 (Implementation)	I have insuffiect knowledge to comment in detail
Section 6 (Related NICE guidance)	I have insuffiect knowledge to comment in detail
Section 7 (Proposed date of review of guidance)	

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I suffer from Prostate Cancer
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	The benifits outway the dis-benefits
Section 5 (Implementation)	It is worth implementing
Section 6 (Related NICE guidance)	Good
Section 7 (Proposed date of review of guidance)	Until Cabazitaxel is proved to be better & available then approve Arbiterone

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	postcode lottery! is my life worth nothing £0
Section 2 (The technology)	how much is my life worth
Section 4 (Consideration of the evidence)	this whole thing stressing me out.if money has been put into developing this lifeline, it is my human right to have it available to me , for me and my family. older men like me have paid all our lives into the NHS and this is how we are treated!!!

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is absolutely disgraceful that mens lives are being sacrificed so that there is sufficient taxpayers funding to pay for, inter alia, some silly womens breast jobs, lesbian IVF treatment etc. I have no problem with funds being used for breast cancer treatment though it now appears that the screening program may, on average, have been causing more harm than good. As a taxpayer,I will seek to actively oppose funding for NICE and the NHS unless this treatment is approved. This is an absolutely outrageous further example of health discrimination against men.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I have a ph d in mathemetics and know more than a little about faulty statistical methods
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	The NICE analysis is based on relativeley small samples and acknowledging that some recover for unknown reasons whilst others die for the same or different unknown reasons - it is mathematically impossible, with the data, as presented, to replicate the NICE conclusion about the drugs effectiveness. The only objective statements by nice are 1 there is no alternative treatment for late stage PC which is as good 2 its too expensive. if this is as good as the nice team can manage they should have the honesty to say so. However this is clearly not the conclusion the NICE wants to draw from its own analysis
Section 5 (Implementation)	not relevent in this case as a cost based decision ignoring patients need has been taken in section 4
Section 7 (Proposed date of review of guidance)	well before that get some serious statistical training. remove the myth that you need a man in a white coat to make this type of evidence based judgement, or state that for simplicity reasons we will ignore mathematics and base everything on the guesses of the stethoscope carriers

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 not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.
Section 2 (The technology)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.
Section 3 (The manufacturer's submission)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is

	my opinion that this drug should be made available to all men in the UK under the NHS.
Section 4 (Consideration of the evidence)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.
Section 5 (Implementation)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.
Section 6 (Related NICE guidance)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.
Section 7 (Proposed date of review of guidance)	I am not a lawyer or a chemist. However I do know from personal experience that abiraterone does extend the life of men with advanced stage Prostate cancer. It is my opinion that this drug should be made available to all men in the UK under the NHS.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I have advanced prostate cancer which was diagnosed over three years ago and which is currently being controlled very sucessfully by Zoladex. I understand that UK researchers have spent over twenty years developing Abiraterone. User trials have been very encouraging. Users report greatly enhanced quality of life with greatly reduced pain so they are able to carry on with a normal life. This includes continuing to work in many cases so they do not claim benefits due to unemployment or ill health. In many cases their life is extended by years rather than months. As a layperson I do not have the technical knowledge to review and comment on the detailed assessment carried out by NICE. However, as an accountant I believe that the cost of this drug to the NHS has influenced the decision. I urge both sides to use their best endevours to reach a financial compromise. The manufacturers need the income to recoup the development costs and hopefully enable them to carry out furthur research. Men with advanced prostate cancer need the drug to give them precious time with their loved ones. This is a world class drug which men need. Do not allow them to die because of a financial impasse.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Nothing.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Preliminary recommendation should be re-appraised. The drug is life extending without impacting quality of life.
Section 2 (The technology)	£2,930 for 30 days supply, suggets circa £12,000 for four months extra life expectancy.
Section 3 (The manufacturer's submission)	No comment.
Section 4 (Consideration of the	The technology makes a compelling case.

evidence)	
Section 5 (Implementation)	no comment.
Section 6 (Related NICE guidance)	Cordinate this Cabazitaxel decision and recommendation with Abiraterone decision.
Section 7 (Proposed date of review of guidance)	If decision goes against Abiraterone, review in 18 months, not 3 years.

Role	Carer
Other role	Partner
Location	England
Conflict	no
Notes	Please consider continuing with Abiterone.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I support 1.2
Section 2 (The technology)	Comments suggest that side effects are manageable

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	section 1.1 does seem to conflict with 1.2 sureley it should be possible for all such conditions to be treated with arbiraterone and not jusy t d simply those who for whatv ever reason are already receiving it .
Section 2 (The technology)	whilst rev cognising the cost of the tablets this should nevertheless not preclude those unfortunate enough to be in need of this life prolonging drug from receiving it . it should also be possible to negotiate a lower cost.
Section 3 (The manufacturer's submission)	the manufacturers submission is far too complicated for a mere layman to comment upon but i see nothing in there which would necessitate changing any of my foregoing comments.
Section 4 (Consideration of the evidence)	no further comments necessary.
Section 5 (Implementation)	implementation should take place nationallay immediately.
Section 6 (Related NICE guidance)	no further comment.
Section 7 (Proposed date of review of guidance)	2015 will be far too late for many thousands of prostate cancer victims. implementation should take place within weeks and not years.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Abiraterone should be made available on the NHS.You have refused Cabazitaxel-a possible alternative. It is the only Eol treatment currently under consideration. It improves life expectancy & quality of life.Side effects are not an issue. It enables some patients to continue working & not draw benefit payments.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It would be totally wrong to not recommend abiraterone purely on the grounds of cost when it has already been proven to be beneficial to patients (see 4.3 below). In addition the non-recommendation of this drug for cost reasons would send the wrong signal to drug manufacturers in their research for medical breakthroughs of any nature and in particular cancer, including prostate cancer.
Section 4 (Consideration of the evidence)	The significance of point 4.3 is being treated as of low importance by the committee.
Section 6 (Related NICE guidance)	The committee should recommend the use of abiraterone until such time as other equally successful but cheaper drugs become available.
Section 7 (Proposed date of review of guidance)	This is too long to wait and should be given a higher priority i.e April 2014

Role	Local government professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Whilst I have little medical expertise, having read the supporting information it appears that the effectiveness of abiraterone in prolonging life expectancy and quality of life is beyond question. The application has been let down by a flawed trial by the manufacturer which potentially has led to an underestimation of the QALY cost. In my opinion, this in itself should not proclude patients and families from being able to benefit from this life-extending treatment.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am in a prostate cancer patient support group of men that provide mutual support to members and men who have prostate cancer. It is a voluntary group with no paid members or employees.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	From actual patient experience the drug has a dramatic effect on life expectation and quality of life. Its should be available for palliative care. It has a huge impact on pain control in combination with other drugs and also can allow some men to resume work and be active in the community.
Section 2 (The technology)	The dosage and cost you quote are only for the first month. Thereafter the cost is a quarter of your initial costings, i.e. £732 per month or the cost you quote is for 120 days not 30 days.
Section 3 (The manufacturer's submission)	If 120 days cost ~£3K then a years cost is ~£9K. If the extended life span is correct, which I believe is wrong and too low(see al-Megrahi who has survived 3 years on this drug), then the cost of an extra 4 months with high Quality of life is ~£9K or ~£27K per year QALY (~£29K for 3 years i/c the first year of treatment)[the

	outpatient visits are common so not i/c in these figures. The patients that were on the trial certainly included some that were so ill they were unable to take the tablets for a significant time and therefore your analysis is invalid. One was so ill before he was on the trial that he was drinking morphine directly from a bottle of medicine as well as being on a syringe pump at the same time. The drug should have been trialled with patients that were actually able to take the drug consistently. A cost of £67K that you quote would mean a life of ~7.5 years on the drug, all of which would be at a significantly enhanced quality of life. I know men who are back at work and productive in the community after taking Abiraterone.
Section 4 (Consideration of the evidence)	You do not state whether the Weibull analysis showed any change in the hazard rate profile. The Weibull distribution is very effective at detecting changes and transition points in the curve. Was there any indication that the dosage could be reduced further or needed to be increased as time elapsed. If NICE can justify the approval of the HPV vaccine at ~£250 per child for all girls (not boys though they are at 5 times the risk)a cohort of 100,000+ and costing £25Bn or more per year to save approximately 180 womens lives per year, then why are NICE so anti men? Dont we count or are we expendable once we reach the end of our productive lives? Your priorities are completely distorted against men and in favour of women.
Section 5 (Implementation)	Do your guidelines take account of the gain or loss to the exchequer of men dying earlier than the expected or normal life span? Do they take account of the benefit to the community of men who work for longer because of the treatment? Do they take account of the extra cost of attendance allowances or hospital care when men are in such pain and suffering that they need 24 hour care.
Section 6 (Related NICE guidance)	In Guide 58 you do not recommend screening. At £7 per test this is a far more effective way of minimising the need for palliative care. However, the downside is the increased bill for pensions for the survivors. To die from PCa is a very painful death and it is preferable totest, monitor and treat when necessary rather than live in ignorance until it is too late and you have the prospect of a very painful death. Abiraterone in combination with other drugs helps with pain control. I am certain if you told men the options you examined in GL 58 that they could have a simple blood test costing £7 or wait until they had inoperable cancer and you were quite prepared to castrate them to minimise the drug bill, then they would opt for testing.
Section 7 (Proposed date of review of guidance)	If you still turn it down then it should be reviewed in April 2013, prior to any parliamentary elections. I do hope that you employ some doctors, some who are men on your assessment team and who are involved with production of any document. None of the 4 women who wrote the GL58 were doctors of medicine and they did not know if you castrated men whether they would be sterile or not. Read the document and see.

Role	Public
Other role	
Location	England
Conflict	no
Notes	Firstly from a perspective of decision making criteria, it appears that the assumptions used by NICE regards number of patients to be treated Abiraterone are widely disputed. This decision is too important to make on questionable assumptions. I would urge further dialogue to get as close as possible to an agreed set of assumptions before making a final decision. When financial parameters are used to calculate if an investment is a feasible one, surely it is important to also consider the cost involved in treating patients who do not get access to drugs in question such as abiraterone. Currently I do not believe that to be part of the equation. Consideration must be given to the cost to treat patients that fare a much more uncomfortable experience and need for additional support, than those successfully treated by abiraterone. My final point is one of morality. Ths successful use of Abiraterone in a number of

	cases brings months and years of extended life and dramatic increases in life quality. The development of this drug has been driven in part by charitable donations from the British public. Their aim was to provide hope and benefits to Prostate cancer sufferers that far outweigh the cost of the drug. As a typical UK tax payer I find it morally unacceptable that we are unwilling to fund this drug for some of our most needy citizens in the UK. However we are prepared to fund breast enlargements, sex changes and gastric bands on the NHS. As a country we have been prepared to house Abdelbaset al Megrahi, a convicted murderer, in a high security prison and then release him on compassionate grounds suffering from prostate cancer. On his return to Libya abiraterone has extended his life for 2 and a half years. Where is the compassion in denying the UK public this treatment?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Firstly from a perspective of decision making criteria, it appears that the assumptions used by NICE regards number of patients to be treated Abiraterone are widely disputed. This decision is too important to make on questionable assumptions. I would urge further dialogue to get as close as possible to an agreed set of assumptions before making a final decision. When financial parameters are used to calculate if aninvestment is a feasible one, surely it is important to also consider the cost involved in treating patients who do not get access to drugs in question such as abiraterone. Currently I do not believe that to be part of the equation. Consideration must be given to the cost to treat patients that fare a much more uncomfortable experience and need for additional support, than those successfully treated by abiraterone. My final point is one of morals. Ths successful use of Abiraterone in a number of cases brings months and years of extended life and dramatic increases in life quality. The development of this drug has been driven in part by charitable donations from the British public. Their aim was to provide hope and benefits to Prostate cancer sufferers that far outweigh the cost of the drug. As a typical UK tax payer I find it morally unacceptable that we are unwilling to fund this drug for some of our most needy citizens in the UK. However we are prepared to fund breast enlargements, sex changes and gastric bands on the NHS. As a country we have been prepared to house Abdelbaset al Megrahi, a convicted murderer, in a high security prison and then release him on compassionate grounds suffering from prostate cancer. On his return to Libya abiraterone has extended his life for 2 and a half years. Where is the compassion in denying the UK public this treatment?

Role	Carer
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone improves patients life and would be imoral to deny or stop.
Section 2 (The technology)	This drug was developed with the support of the population,well done.Now use it and develop it to help men with early stage prostate cancer.
Section 3 (The manufacturer's submission)	No price for life!
Section 4 (Consideration of the evidence)	Personal evidence of improved quality of life and less pain after my husband began taking Abiraterone.
Section 5 (Implementation)	Implementatio shoul be immediate to the men who need the drug.The same as women needing breast cancer drugs.

Section 7 (Proposed date of review of guidance)	April would be a good month to review.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	How is it that the NHS can always find the money to treat self inflicted illnesses such as those caused by alchohol, smoking and over eating and yet the money is not available to help those who have life limiting illnesses through no fault of their own? Preventing the use of drugs such as these is a discgrace and it is time we got our priorities right!

Role	Patient
Other role	
Location	England
Conflict	no
Notes	men with prostate cancer should be given the chance to have abiraterone. This life extending treatment should be available on the nhs. What if it was your dad, your partner, your son. Would you not want to give them the best possible chance to extend their life.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a prostate cancer patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I do not agree with the Appraisal Committees preliminary recommendation. If it is considered to be clinically sound to continue treatment then it seems inconsistent not to continue to provide it, presumably on grounds of proven efficacy and therapeutic value.
Section 2 (The technology)	Surely the primary case is on grounds of proven efficacy and therapeutic value and price consideration is secondary, having regard to the mitigating steps taken by manufacturer.
Section 3 (The manufacturer's submission)	the manufacturer has made a very detailed case. Where is the full point by point rebuttal to this detailed case, and is it sustainable in relation to efficacy and therapeutic value? There is no counter statement to the benefits (para 4.3)
Section 4 (Consideration of the evidence)	It would be interesting to know whether members of the committee in a similar clinical situation would press to be provided with Abiraterone and Prednisolone
Section 5 (Implementation)	Noted
Section 6 (Related NICE guidance)	Noted
Section 7 (Proposed date of review of guidance)	Earlier review desirable if approval not already given.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Personal history available on secure request
Comments on individual sections of the ACD:	
Section 1	Making abiraterone available on the NHS will give hope of more years of family life

(Appraisal Committee's preliminary recommendations)	since, at present, there are few drugs capable of slowing the inexorable progress to death within 3-5 years. I think the consequences of abiraterone not being made available on the NHS would be devastating to patients and carers, and any decision not to make abiraterone available would be very wrong. Rejecting abiraterone would give the impression that the NHS doesnt care and that the financial side of the issue has outweighed the human side. Being approved for use but not funded on the NHS would create the very worst rich-poor and post-code lottery divide. Patients would feel that they had been denied something of potential benefit ? that they are deemed not worthy of another chance. If standard hormone and chemo treatment had ceased to be effective and abiraterone was not available as a suitable alternative then the only alternative would be palliative care, leading to a decrease in morale and depression knowing that a drug is available that can prolong life which is not being made available.

Role	Public
Other role	
Location	England
Conflict	no
Notes	I must ask NICE to change their draft decision and allow the use of Abiraterone for use by any man that would benefit from its use to allow him an extension of his life. Any person should be offered any chance to extend their life, if they so wish. Thank you.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I must ask that NICE change their draft decision and allow any man to be prescribed with Abiraterone, if it would offer him an extension of his life, if he so wish it.

Role	Patient
Other role	NHS Consultant
Location	England
Conflict	no
Notes	Partially retired NHS Consultant in Anaesthetics abd Chronic Pain Relief. Chairman of Reading Prostate Cancer Support Group
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I do not agree with the committees opinion and decision
Section 2 (The technology)	How does the cost compare with other drugs used in similar situations that are already in use for other conditions? How much does it cost to look after a terminally ill patient for a month? Does the use of abiraterone actually reduce the cost of care in end-stage prostate cancer?
Section 3 (The manufacturer's submission)	For a layman (and even most medics) this information too complex to understand. If the lay-public are to respond they need information which is intelligible to them and written in language they can understand.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	As a patient I feel it is reasonable to expect treatment of proven worth such as ABIRATERONE to be made available to me as and when it is required to prolong my life.You cant put a price on living as opposed to dying which seems to be the

	case.I feel Nice should get round the table with the suppliers to negotiate a better price for NHS patient treatment for the benefit of sufferers.
Comments on individual sections of the ACD:	

Role	other
Other role	Husband has enlarged prostate not cancerous at this time
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 5 (Implementation)	Cost cost cost. Are the powers that be never affected also not able to pay for treatment
Section 6 (Related NICE guidance)	NICE allows this country to fall behing the rest of the world with COST as its only reason
Section 7 (Proposed date of review of guidance)	By 2015 how many men will lose their lives and die a horrible death because NICE deems it correct to wait until then

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 read all of this before comment. How can this drug, which clearly works, be made cheaper if it cannot be used? Why is it OK on cost grounds to condemn a man to an early death yet have limitless funds to keep alive someone who wants help to die. The technical issues are beyond my ability to comment

Role	Patient
Other role	
Location	Scotland
Conflict	no
Notes	As a prostate cancer sufferer I would hope that any new treatment or drug abiraterone would be made available by NICE that would help prolong life.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a 63 year old patient with advanced prostate cancer. My life span has been greatly reduced due to this disease and I do not have a good quality of life to enjoy all the natural things people of my age would expect.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	All drugs should be made available on the NHS to all that need them. Money should not be a factor with regards to saving life. Decision makers would have a different outlook on their judgement if they were a sufferer.
Section 2 (The technology)	Why should the cost of advancing technology interfere with saving life. It certainly is not a problem when we consider the nations defence. £2930 for a life.

Role	other
Other role	Friend of patient
Location	Other
Conflict	no
Notes	
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	My friend Chris is currently on the drug. This is what his wife days: "Chris is responding remarkably well. His psa fell from 200+ to 80+ in just 3weeks. He now has no pain at all and his nausea is virtually gone.As a result his quality of life has improved loads, so we hope to go away for a few nights next week." seems pretty powerful to me.
Section 2 (The technology)	i am not qualified to comment
Section 3 (The manufacturer's submission)	i am not qualified to comment
Section 4 (Consideration of the evidence)	it evidently helps some men

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This draft guidance is a bitter blow to thousands of men and their families - and must be reconsidered. Studies on abiraterone show that it can prolong the life of men in the final stages of prostate cancer by an average of about 4 months and improve the quality of their lives. The drug is one of the biggest breakthroughs in the treatment of the disease for many years. It offers men the possibility of extending their lives at a time when there are no other available treatment options, except those that just control the symptoms of the disease. Unless NICE recommends that the costs of abiraterone should be covered by the NHS, men with advanced prostate cancer in England and Wales will face a postcode lottery trying to access this important new medicine. This is unacceptable.

Role	Carer
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	At first appearances people think that prostate cancer is an old mans disease, in our society the value of older peole is given little worth, and this is perhaps one of the reasons why NICE have made their decision. Thinking that little care or notice will be given to old men dying earlier. But, prostate cancer is not an old mans disease, and is the most common form of cancer in men. My husband was diagnosed at 36, when I was 3 months pregnant, we were told that he would be here to see the baby being born, but that they werent able to say how much longer hed be around for. 10 years later he has advanced cancer with metastases in the pelvis and spine, we are on a low income and would only be able to fund this medicine by fund raising. We have 4 children who all want their Dad to be around for as long as possible, by denying him this treatment you take that away. My opinion is that mens cancer is viewed in a very different way to womens, they are being treated as second class citizens.

Role	NHS Professional
Other role	
Location	England

Conflict	no
Notes	I am also a patient with locally advanced Ca prostate.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel this drug should be funded by the NHS throughout the country .Potential funding via the drug cancer fund might lead to a post code lottery effect. This drug is effective & relatively non toxic.I think you should offer a deal to the manufacturers it will be used on selected patients (ie those who will benefit from Abiraterone)& because of its increased use the price per patient will be discounted.

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1.1 to be able to offer patients the best treatment for advanced prostate cancer which is castrate resistant, Abiraterone should be recommended for those patients progressing after Docetaxel chemotherapy i.e. disagree with 1.1
Section 2 (The technology)	accept
Section 3 (The manufacturer's submission)	the cost estimate, granted is very high, but palliative benefits as well as prognostic benefits
Section 4 (Consideration of the evidence)	expensive but effective!

Role	NHS Professional
Other role	Health Professional private
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1.1 should add that the recommendation is because it is to expensive, so that readers do not assume it is of no benefit.
Section 2 (The technology)	2.3. This is the problem. It is an outrage that the drug company have set such a high price. This drug was developed in the UK ICR and the studies funded by CRUK and the british public who donate. There needs to be negotiation on price so that this treatment is available to UKL patients on the NHS. The current price is completely unaffordable. To treat 5000 patients for a year will cost almost 200 million pounds and no one in the NHS or UK can justify this.
Section 4 (Consideration of the evidence)	I have patients on Abiraterone through the cancer drug fund and see first hand how it is improving patients quality of life and extending their survival. To have this treatment removed from patients grasp will mean that some will do everything including selling there homes and going into debt to get this drug privately. NICE must negotiate hard to reduce the price of Abiraterone. There is a risk that the drug company will walk away from the UK market. This is just one drug with a survival advantage of a few months. How much will Pharam want for future drugs? There should be laws passed to stop pharma running drug development and looking after their own interests ahead of the benefits to patients.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Firstly can I say that it was not easy for me to find the appropriate way from your

	web site to make appraisal consultation comments. Ive only found this page thanks to kind assistance from Jessica Fielding in your Communications Executive. I was diagnosed with an advanced form of prostate cancer in 2003. It had metastasised to my bones and the only treatment then open to me was hormone therapy and palliative end of life care, such was the lack of available drugs to treat the disease. To me (and my wife) that was totally unacceptable. With a hope born of desperation I agreed to participate in a drug trial at The Royal Marsden, working in collaboration with the Institute of Cancer Research. That first trial drug improved my condition and led to a second trial on a different treatment and then a third before I was enrolled in late 2006 on a post-chemotherapy Phase II trial for Abiraterone. This drug stabilised my condition to such an extent that I took it, as part of the trial, for three and a half years (44 cycles) with very few minor side effects before I moved on to yet another new drug trial (Olaparib) in late 2010. Such is the way in which statistics seem to be interpreted that the success of several years on the Abiraterone drug trial ? not only for me but also for many other men ? is interpreted by NICE as ?prolonging life for an average of four months?. That interpretation is so skewed and many men on the trial, such as myself, have several active years to be thankful for. - In my case, before I was able to transfer to another trial for a new drug more appropriate to my condition. (The ?Olaparib? trial I am now on is based on breakthrough technology in genetics and molecular pathology which identified a drug more relevant to my particular prostate cancer). Throughout my treatment with Abiraterone I led a full and active life, working full time and never claiming any form of benefit. I?m now 63 and feeling fit and well thanks to these treatments. ? and I?m not by any means the only man who can relate a similar story thanks to Abiraterone! - Sadly our voices (and statistics) seem to be ignored. On an emotive level, a refusal for Abiraterone (and to this I would add the recently declined Cabazitaxel) by NICE seem like hammer blows to patients desperately waiting for a drug that will fight their disease. There are so few options for advanced prostate cancer treatment other than end of life palliative care. Consider too the effect on dispirited researchers and clinicians here in the UK who have spent many years working on the development of these new drugs which were originally discovered here in the UK. Who could blame them if they leave the UK to seek research posts in other countries where their work will be appreciated and put to the beneficial use of patients without quibble over cost? Also, lets not forget all those who have spent considerable efforts fund-raising so that these new drugs can be researched and developed in the first place. - Its a kick in the face to them too. Please, please reconsider your decision on Abiraterone. I hope you will be aided in this by drug companies who can see more compassion than profit when setting a price on Abiraterone. Its use will have a significant and positive effect on men with advanced prostate cancer for many of whom there is no alternative treatment. Thank you.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I was diagnosed with an advanced form of prostate cancer in 2003. It had metastasised to my bones and the only treatment then open to me was hormone therapy and palliative end of life care. From early 2006 I took Abiraterone, as part of a trial at The Royal Marsden, for

	three and a half years (44 cycles) with very few minor side effects - leading a full and active life and working full time - before I moved on to yet another new drug trial (Olaparib) in late 2010. This was more than ?prolonging life for an average of four months?. Thanks to Abiraterone I have several active years to be thankful for. - In my case, before I was able to transfer to another trial for a new drug more appropriate to my condition. (The ?Olaparib? trial).

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone has been a great development in recent times as a treatment for late stage prostate cancer. NICEs recommendation is another clear message that the NHS places men with prostate cancer as a very low priority. This is for many men their last lifeline. The recommendation from NICE is cruel

Role	Patient
Other role	
Location	England
Conflict	no
Notes	As a prostate cancer sufferer I find it disappointing that NICE should decline Abiraterone on cost grounds. It a pity men dont seem to get the same access to life saving drugs as women with breast cancer do - this is discriminatory.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Given that prostate cancer is one of the poor relations of the cancer family I firmly believe that abiraterone should be made avaiolable on the NHS
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe the Appraisal committee are wrong

Role	Public
Other role	
Location	England
Conflict	no
Notes	Please allow use of Abiraterone for final-stage prostate cancer

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	I would urge NICE to take in the wider scope of cost effectiveness. Men with castrate resistant prostate cancer who have disease progression following chemotherapy are likely to run into considerable problems that cost the NHS a great deal of time and money. We know that abiraterone is an effective drug in this scenario, delaying progression. Patients receiving this drug are therefore less likely to require early intervention for renal failure due to disease progresion delaying the need for hospital admission for

	surgical intervention with trans urethral resection of the prostate or radiological intervention with nephrostomies. Plus saving the need for repeat procedures/interventions. From a quality of life perspective the use of the drug is likely to delay the progression of the disease to bones and therefore reduce the need (and expense) of both simple and complex pain relief. If symptoms of disease are delayed there will be less of a drain on clinicain, hospital and community medical teams. The treatment itself is well tolerated and easy to deliver and monitor.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	whilst based only on 1 sample the evidence for allowing the further use of abiraterone is compelling in terms of the time added to life and pain relief
Section 4 (Consideration of the evidence)	much of the evidence is too technical for me to understand but my simple view is that men suffering from this terrible disease should be given the opportunity to use a drug which clearly appears to extend life and ease pain

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The drug should be available and used under medical supervision in the interest yhe patient and research

Role	Public
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I am very impressed by what I have learnt, including from those who have had direct practical experience, and this takes me to the conclusion that the question of affordability must be answered as to ensure that this drug is provided to all in clinical need.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This preliminary recommendation is discraceful. The Appraisal Committee should be ashamed of itself. Speaking as a British Taxpayer I am appalled by this recommendation.
Section 2 (The technology)	The technology has been proven to be clinically effective. Moreover it was developed in the UK.
Section 4	The evidence is overwhelming that abiraterone works and yet the government

(Consideration of the evidence)	seems determined to deny it to people who need it. I thought we were meant to live in a compassionate country?
Section 7 (Proposed date of review of guidance)	Too Late!

Role	other
Other role	Friend of sufferer
Location	Scotland
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am not a medical expert but have seen a significant improvement in my friends condition since he has been receiving this treatment. I appreciate there are difficult decisions to make in these difficult times and that this is a fairly costly treatment but that has to be weighed against the improvement in the quality of life not just for the individual but for the carers and immediate family as well. I strongly support those who want to see its use continued as it should not be down to a postcode lottery or people with plenty of funds to get access to this treatment

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 not an unintelligent person but I am also not medically qualified, and as a lay person I have found the complex level of technical detail in this document very difficult to follow. However, rather than being deterred from making any comments (which may or may not have been the intention) I have decided to write from the heart. I am aware I cannot identify who, but somebody very close to me has prostate cancer. I have read about the development of Abiraterone with selfish interest and hope, that should they need this drug at some time in the future it would be made available to them, but now that hope is very much at threat of being snatched away. There have been many reports of men with advanced prostate cancer having their lives extended by YEARS, not months, through taking Abiraterone, including the man responsible for the atrocities at Lockerbie. For those men whose lives have been extended by months, they have been able to have a relatively pain-free existence for the last few months of their lives, and to not allow this to happen is inhumane. Cancer is a cruel indiscriminate disease that 1 out of 3 of us will have to fight at some point in our lives, CONTINUED
Section 2 (The technology)	CONT with these numbers set to rise in coming years. For the other 2 out of the 3, it is extremely likely they will have to endure the helpless torture of watching a loved one suffer. So when it comes to cancer Mr. Cameron, yes we ARE all in this together. We all know about the national deficit but we are still a comparatively rich country and in a civilised society it is just plain wrong, morally and ethically, to put a price on human life. Please do not deny people this life extending and pain reducing medication. Thank you for taking the time to read this.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	No. I just wish to express the view that the NHS should allow the prescribing of

	Arbiraterone in suitable cases and it should not be restricted on cost grounds alone.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	See earlier note

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I was diagnosed at age 60 with a high PSA reading of 56. Two years of watchful waiting was followed by a standard and then by template biopsies. Cancer was found in the prostate with a gleason scale of 9. Treatment, in the form of Brachytherapy and external beam radio therapy. This was followed, initially, with ZOLODEX injections but because of adverse side affects in my joints was changed to PROSTAP. In December 2011 my PSA rose to 22 and scans revealed that the cancer had migrated to the pelvic bone. In addition to the Prostap,I am now having daily hormone treatment of Bicalutamide. It is known that hormone treatment is limited by the time that the cancer finds a way arround it and alternative treatment has to be administered. I am stiil only 64 years of age and would like to think I have many active years ahead of me. With all the information now available regarding abiraterone, I am in little doubt that this drug will give me and many others that bright future to share with family and in particular with grandchildren. I am fully aware that cost is a major consideration but what price can you put on watching your grandchildren grow and develop.

Role	Patient
Other role	cancer suport member at HELEN WEBB HOUSE
Location	England
Conflict	no
Notes	Iwas first diagnosed 29/7/2005 my psa was 3.6 I have had various hormone treatments, scans, radio therapy, my psa is now up to 47 Iam now a the stage when abiratarone would give me a chance of a better life I am 85 years old
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	this should be judged by use to patients not cost
Section 2 (The technology)	should be approved by NICE

Role	Public
Other role	
Location	England
Conflict	no
Notes	I have prostate cancer
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	In my opinion it is not a good use of NHS funds to pay for a treatment that extends life by 3 months. there are som ant aother areas of healthcare that would provide greater benefits admittedly to a differemt group of people.

Role	other
Other role	Chairman Proactive prostate cancer self help group
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1	It would not be right to take a life giving drug away once started but everyone

(Appraisal Committee's preliminary recommendations)	should have the opportunity.
Section 2 (The technology)	This is all very generous but what about people with the same need but who cant afford to pay. Creating a two teer system, the have and have nots
Section 3 (The manufacturer's submission)	This is all very well but a good product should not be restricted by cost.
Section 4 (Consideration of the evidence)	Moving on from the costs and justification I feel that if the members making these decisions or consultations actualy had a prostate Cancer problem would their attitude change even an extra 4 months of life is sweet when there is no hope.
Section 7 (Proposed date of review of guidance)	Why so long 3 years people NEED help today they wont be here in 3 years

Role	Carer
Other role	Wife
Location	England
Conflict	no
Notes	Men taking abiraterone, at a stage of their disease where there are very few or no other treatments, are showing very encouraging signs of the cancer retreating or stabilising giving them extension of life. It saddens me that a mans life is measured in finance rather than compassion, especially as this drug was discovered and trialled in England yet English men will not be able to benefit from it unlike our European friends. There are other encouraging novel agents in trial at the moment targeting PCa and if they prove successful it will provide competition for abiraterone probably bringing the price down. This would make it doubly unfortunate for those men who need the drug at this moment in time, being denied access to it and forfeiting their lives. The NHS was set up so all people in this country can have access to optimum treatment, not just the rich.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	At last we have an effective treatment for C.R.M.PCa., but too many people need it! A drug researched in this country cannot be given to people in this country. I still do not understand the logic.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	NHS patients should be able to be treated with Abiraterone. I understand AxaPPP, Bupa and WPA cover this treatment. Is it acceptable that only people with medical insurance can be treated. Are their lives more valuable than those with only NHS treatment available? NICE can and should ensure a level playing field.

Role	Public
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My father in law is currently doing really well with this drug, it should be available to all.
Section 2 (The technology)	if Bupa fund it for their clients then it must be getting good results and therefore worth the cost
Section 3	what is the point of trialimg it and drug research if it is then not licenced?

(The manufacturer's submission)	
Section 4 (Consideration of the evidence)	the cancer charities are endorsing it, that speaks for itself!
Section 5 (Implementation)	this is a rediculous form for the general public to comment on, obvioulsy trying to baffle people with all this jargon so they will not bother to leave a comment!

Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1. I am a very angry patient benefitting from this drug currently 2.Why are the private sector health insurance provider community (BUPA, Aviva etc.) paying for it for their clients, if it is not producing significant results? They must think it?s cost effective? 3. Negates the benefits of Government & Charity funded successful research and trialling. 4. Totally out of sync with the strong endorsements of the leading Cancer Charities (Cancer Research UK & Prostate Cancer) 5.Your consultation site is a joke - how do you expect the average person to follow the complexity of this document. It seems to be a deliberate attempt to put off legitimate concerns.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone has shown a positive response may be gained after docetaxel.The chemotherapy often instils such a further hormone treatment response.
Section 2 (The technology)	Men have survived several years after chemotherapy solely on hormone treatment (when chemo has failed), thus showing further hormone response.
Section 3 (The manufacturer's submission)	Abiraterone works for some men. Results are seen quite quickly.
Section 4 (Consideration of the evidence)	Abiraterone is a tolerable drug. And more acceptable than chemotherapy in many ways to the patient.

Role	other
Other role	My Dad passed away from prostate cancer 2 years ago
Location	N Ireland
Conflict	no
Notes	Id like to ensure that men in the UK (including Northern Ireland) who need abiraterone - an important, new life-extending drug for prostate cancer ? can get it for free from the NHS. I ask that you please recommend abiraterone for routine use by the NHS. Thank you
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Id like to ensure that men in the UK (including Northern Ireland) who need abiraterone - an important, new life-extending drug for prostate cancer ? can get it for free from the NHS. I ask that you please recommend abiraterone for routine use by the NHS. Thank you

Role	Patient
Other role	Retired
Location	England
Conflict	no
Notes	The NHS/Nice should be in consultation with the Drug Manufacturers to reduce the costs of these drugs and therefore benifit the paitents
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I agree with part 1.2, it is up to the patient and his Specialist to decide on treatment not face less administrators who do not know the circumstances.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is a strong preference that this drug should be available to all men that need it to prolong life and reduce suffering.
Section 2 (The technology)	Please expolre the reducion of cost to enable this drug to be more widely availble.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a metastic prostate cancer sufferer but some way off from needing the benefits that abiraterone might bring. I am very concerned and disappointed that NICE should consider recommending that the drug not be financed by the NHS in Enagland and Wales.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a metastic prostate cancer sufferer but some way off from needing the benefits that abiraterone might bring. I am very concerned and disappointed that NICE should consider recommending that the drug not be financed by the NHS in Enagland and Wales.

Role	other
Other role	Friend of man with prostate cancer
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My friend who is suffering from prostate cancer has been taking this drug and it has noticeably imoroved his quality of life - provision should not be restricted.

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Cost effectiveness - how do you put a value on life? £100 (ex vat - is vat reclaimable by the NHS?) looks expensive, but can the overall cost be compared to that spent overall on breast cancer treatment? I am thinking nationwide here. When a drug is proven to prolong/save life, it should be prioritised over treatments which are more cosmetic (e.g. IVF)

Role	Patient
Other role	Retired teacher and ex-social worker. Independent professional witness.
Location	England
Conflict	no
Notes	Author of book ISBN 978-0-9549935-1-1 September 2009. "Prostate Cancer: A 21st Century Perspective. Natural history, ecology and sociology of a malignant epidemic." This book may be copied provided the authorship is acknowledged. A free copy is available on request to the author. The publication runs to about 200 pages including References (numbered) and Index (alphabetic).
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Section 1.1 does not recognise the substantive "social value added" element of taking abiraterone ("in combination" as described, or otherwise by NICE) in the context of family, friends, society and economy. A methodology is required to evaluate and audit the "social value added" contribution (to the wider social matrix) of people receiving abiraterone. Section 1.2 Should recognise, and be prepared to move constructively in the context of IAS ("intermittent androgen suppression") as previously documented by NICE after 2008. It has been found that intermittent use of castration inducing drugs / intermittent recovery of natural androgen levels may significantly increase survival and quality of life in people with advanced metastatic prostate cancer. Simple withdrawal of abiraterone should not be regarded as a "one- shot" trigger point after which further abiraterone would be considered "useless". Indeed, abiraterone assisted repeated episodes of "androgen withdrawal" and "androgen exposure" need further

	investigation for their therapeutic value. Abiraterone has the potential to open up a whole new field of enquiry and therapeutic application in people with advanced metastatic prostate cancer.
Section 7 (Proposed date of review of guidance)	NOTE: The "boxes" are too small to be read / written-to and tend to fragment the text that is entered.

Role	other
Other role	Daughter of patient
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 2 (The technology)	Why is this discount confidential? Patients need to make informed choices about treatment. This is not easy if pricing information is not easily accessible
Section 4 (Consideration of the evidence)	It is proved that abiraterone offers improved quality of life, relief from pain and extends life by up to 4 months. The further benefit of being able to take the medicine at home cannot be understated at a time when every moment spent at home with family is crucial. Complex costing considerations aside, I do not see the logic in blocking a drug which according to your report appears to be the only useful option after docetaxel. Mitoxantrone is said to be rarely prescribed in the UK as patients do not benefit from extended life. In the same paragraph this is contradicted by stating that actually 20-30% of patients receive it - why if no benefit? Surely this is poor use of funds that could be diverted to pay for abiraterone. As chemotherapy should not be repeated what options are advanced cancer sufferers left with? Very few it would seem. If you do not recommend this treatment you are consigning thousands of patients and their families to a miserable end-of-life. This can and should be avoided.

Role	Public
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Simply put..after skim reading the above, patients should have the opportunity to take this drug if they can benefit and extend their lives. At a base price of what appears to be 100 pounds a day, that is good value if someone has paid into the NHS for all their working life.

Role	Local government professional
Other role	
Location	England
Conflict	no
Notes	I am commenting on this as a private individual. All the comments are mine alone.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that abiraterone provides considerable pain and other relief during the latter stages of a patients life. The difference it can make surround quality of life and dignity, for those reasons alone it should be available. In addition, it can also allow a patient to provide for themselves for far longer thus reducing the cost of care.
Section 2 (The technology)	The side effects are a matter of judgement between the patient and doctor, there is clearly a trade-off here and this should not be a reason to withold the drug. I have addressed the cost issue above, abiraterone can allow the patient to provide for themselves thus reducing the cost of care.

Section 3 (The manufacturer's submission)	This is very technical and of limited use to a layman. My comments about dignity, pain relief and reduced care costs remain.
Section 4 (Consideration of the evidence)	While it may not meet the criteria for end-of-life treatment that does not mean to say that those criteria are those that would be approved by a lay audience. I am concerned that this decision is weighted by the cost of the treatment rather than the effect that patients may experience. There will clearly be a variation of effect among patients, so the decision whether to prescribe this drug must be for the doctor and patient to decide clearly it wont be suitable for all.
Section 5 (Implementation)	I have not comments on this part
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No comment

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	This drug has great potential to increase life by years, as well as reducing the amount of pain experienced and so improving their quality of life. It has very few side-effects beyond what prostate cancer patients are already used to in their previous treatment. It is easily administered and after the initial months can be reduced in quantity, thus saving some of the cost. It can enable men to stay in employment for longer, so they will not have to claim benefits for so long ? a saving for the State. There is currently no other comparable treatment. Many people have contributed through Cancer Charities etc. towards the cost of developing this drug. For it to be rejected now will discourage many from donating to further research if this can be the end result.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	As an ordinary "man in the street" the sheer volume of information here is very difficult to take in. I will say that Ive been informed that on the trial men on the placebo started dying after 5 months which is where ?drug extends life by 4 months? comes from. Obviously not all the men on abiraterone died suddenly after 9 months and a day! - but the trial ended at 9 months. So the fact that some, or even all, might still be alive for years is not taken into account as it is outside the trial period! This makes no sense to me whatsoever. Ive had the misfortune of watching my father die through prostate cancer and would not wish this on anyone. My own prostate has been removed and we are hopeful that all the cancer was removed with it so I have no vested interset in the drug. I feel that everyone should be given the chance to take the drug if it could improve both the quality and length of their life. One day it could be you!

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 with the first recommendation. Abiraterone is a last hope for men in this condition.
Section 4 (Consideration of the evidence)	The Committee has underestimated the importance of a treatment for men with advanced prostate cancer. A short extension of life can be very significant. It also provides hope.
Section 7 (Proposed date of review of guidance)	The review date should be brought forward if NICE maintains its present position.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why is it not recommended? Extending someones life should be the number 1 priority
Section 2 (The technology)	Access to this drug is imperative. It can prolong life especially a working life in younger men and also give quality of life
Section 4 (Consideration of the evidence)	If the results show a benefit to people with prostate cancer even if it only gives them an extra 3 months then the decision should be reversed people should never become a cost effective decision why? because the vast majority have spent a lifetime paying into a system ruined by politicians and mismanagement
Section 5 (Implementation)	cost cost cost sick of fhearing about it
Section 6 (Related NICE guidance)	no comment
Section 7 (Proposed date of review of guidance)	reverse the decision

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This decision by NICE should be reversed. this is clearly an invaluable drug
Section 2 (The technology)	Once the drug is made widely available,and is mass produced, the cost should significantly reduce

Role	Carer
Other role	Wife/ Daughter
Location	England
Conflict	no
Notes	I am currently providing end of life care for two family members.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	By not recommending this treatment a valuable option is removed from men in desperate need.
Section 2 (The technology)	The cost that Janssen intend to charge the NHS for Abiraterone makes it prohibitive to most men.I don`t see many PCT`s agreeing to pay that cost, so in effect it would

	create yet another cruel post code lottery. What is the point of developing new drugs if costs make them inaccessable? They need to be asked to look again at their charges.
Section 3 (The manufacturer's submission)	Having followed the progress of trials and asked Oncologist opinions,they were excited by the results and of being able to offer their patient`s an alterative treatment option. They considered the eventual cost not to be an issue to worry about! Can the Committee find more favourable ways of evaluating the manufacturer`s data?
Section 4 (Consideration of the evidence)	The Committee`s decision is hard to understand by the men and families that were hopeful of getting a treatment which offered a little more time together.It is so upsetting to feel abandoned and undervalued by the Country that you have loved and served.
Section 5 (Implementation)	Please reconsider this dreadful decision, lobby Janssen to revise their costs down and make Abiraterone available to all men in England and Wales that need it. Thank you.

Name	John Gear
Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a prostate cancer patient whose drug of Prostap is still effective. For How Long?? Abiraterone is likely to be the last effective drug for me. I need it to be available when other drugs cease to work.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agreed
Section 2 (The technology)	This sounds reasonable
Section 3 (The manufacturer's submission)	Too technical for an informed response

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am a member of the High Peak Prostate Support Group and the PCS North West Executive Committee.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I strongly feel that Abiraterone should be made generally available on the NHS without delay for the following reasons: During the 9 month trial no one on Abiraterone died. Men on the placebo strated to die after 9 months. If the trial had continued survival on Abiraterone could have been much longer than 4 months. The costs of the drug could be offset by heling tp keep men in employment and not having to claim benefits because of ill health. Patients on Abiraterone would enjoy greatly increased quality of life with much reduced pain. The drug is very easily administered, just 4 tablets a day, at home (or wherever convenient to the patient.) The drug dispalys very few adverse side effects. There are no alternative treatments currently available the alternative is death. I urge you to re-consider the general use of this drug in a similar way to the decision made on breats cancer treatment (Herceptin?)

	Please dont leave men to die when there is an effective treatment available. Thank you
Section 7 (Proposed date of review of guidance)	Dont wait until 2015. We need this drug now. Please review your decision and make Abiraterone available on the NHS immediately. Men deserve an even break.

Role	Carer
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The trials with abiraterone were very successful and gave men with chemotherapy resistent treatment hope. Why deny men a better quality of life is beyond me.this new technology
Section 2 (The technology)	This new technology is a life saver for men when all other treatments have failed. The side effects are minimal and will give man a better quality of life. To deny abiraterone to men would be a death sentence
Section 3 (The manufacturer's submission)	Abiriterone has been proven to prolong a longer and better quality of life, to withdraw it because of cost effectiveness would be very cruel
Section 4 (Consideration of the evidence)	Men with advanced prostate cancer should be given the chance to take abiriterone as it has been proven to extend life, hopefully by years and not months.As abiriterone is
Section 5 (Implementation)	if this drug was available to men at an advanced state of prostate cancer and can be administered at home orally then the need for hospitalisation and nursing care would diminish.
Section 6 (Related NICE guidance)	If prostate cancer screening was available nationwide as breast screening is for women then a lot of men would not be in the situation of fighting to keep abiriterone on the NHS.
Section 7 (Proposed date of review of guidance)	I hope NICE will review abiriterone favourably to enable men to have a better quality of life and to extend their life.

Role	Public
Other role	
Location	England
Conflict	no
Notes	I am a member of the PROSTAID charity in Leicester raising funds to support prostate cancer sufferers in Leics. Rutland and Northans. Ibelieve Abeaterone has the potential to increase life by years not months and that the quality of life would be greatly improved with much less pain. The medication is very easily administeredand has very few side affects. In some cases none. At this time there is no other treatment meaning death for the patient.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Iagree that the treatment should continue as long as the patient and clinician feel it is appropriate
Section 2 (The technology)	I do not consider myself qualified to comment on the technology but agree the treatment remains in place as recommended
Section 3 (The manufacturer's submission)	Once again Ido not feel I can answer except to say thank goodness the manufacturers have developed this drug which offrs hope to so many men
Section 4 (Consideration of the	How do you put a price on a mans life.

evidence)	Obviously the NHS FUND ARE limited BUT IF THE DRUG IS AFFORDABLE IT SHOULD BE PROVIDED
Section 5 (Implementation)	tHE DRUG SHOULD BE AVAILABLE NATIONALY NOT LOCALLY SO THAT IT IS AVAILABLE TO ALL WHO NEED IT. No post code lottery
Section 6 (Related NICE guidance)	Seems to be fine.No other comment
Section 7 (Proposed date of review of guidance)	3yrs. from now seems very reasonable.

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 do feel that people diagnosed with prostate cancer in the future should have the option to be given this drug if thought appropriate. I also understand that it can keep men working longer and so save claiming benefits and gives longer life (up to 15 months or more) with less pain and can be easily taken at home. I do think we should be able to pay for this treatment for our cancer sufferers. It is a Third World attitude that we cannot afford to pay for pills for sufferers!

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It has been proven that arbiterone in combination with prednisone or prednisolone is an effective treatment for men with advanced prostate cancer that has stopped responding to other hormone and chemotherapy treatments. This decision will deny many men who are suffering, the opportunity of living a more dignified life.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 2 (The technology)	Easy to administer and take.
Section 5 (Implementation)	No medical alternative, eases pain,hence improves quality of, and prolongs,life.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agree with 1.2
Section 2 (The technology)	why should cost enter the equation surely if it prolongs a persons life cost is inmaterial
Section 3	why are costs involved????

(The manufacturer's submission)	
Section 4 (Consideration of the evidence)	any drug that can increase life expectancy should be used
Section 5 (Implementation)	again this appears to be all about costs
Section 6 (Related NICE guidance)	why do you take so long to approve a drug that has the possibility to save or extend a persons life
Section 7 (Proposed date of review of guidance)	why wait until april for some it may well be to late

Role	other
Other role	Daughter of deceased Prostate Cancer [Metastatic, castration resistant] Father
Location	Europe
Conflict	no
Notes	My father died from Advanced Metastatic Prostate Cancer in November 2011
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Yes, people should be able to continue this drug.
Section 2 (The technology)	Manufacturer needs to lower price and make this drug readily more affordable
Section 3 (The manufacturer's submission)	This has been shown to extend life for a MINIMUM of 4 months and upto 5 years. Men will benefit from this drug
Section 4 (Consideration of the evidence)	The cost of life far out weighs all other concerns. This is a travesty if it is disallowed because of cost. What cost for human life?
Section 5 (Implementation)	Costing ? Please make this work, and REDUCE the cost. This MUST be made available
Section 6 (Related NICE guidance)	This also needs to be made available to men via NHS route
Section 7 (Proposed date of review of guidance)	I am expecting that this date will allow funding via the NHS

Role	other
Other role	Daughter
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	is the drug recommended in chemo naive patients?
Section 3 (The manufacturer's submission)	What trials have taken place which look at effect of early use prior to second line treatments.
Section 4 (Consideration of the evidence)	Many men will have contributed their whole working lives to our tax system only to be discriminated against as just not worth it as they are facing no alternative apart from gruelling chemo or death.
Section 5 (Implementation)	years of research funded by tax payers and charity donations could be wasted if thi drug was ni licences dont stifle the one major recent positive step in the fight against prostate cancer more men will suffer young men as well as old are in need of more optios.

Role	Patient
Other role	
Location	England

Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Now, after all else has been tried, I face a slow and, despite hospice support, painful death. I seek a period when, from my current low and weak state, I may still be able to spend some quality time with my family. After finding docetaxel destroyed my quality of life, I stopped the treatment after five cycles. I now want to try abiraterone to see if it will provide something better. If it does not improve my quality of life, I shall discontinue the course - longevity has never been the issue for me at the age of 76, after a good life and I would not wish to deprive other patients of resources simply to eke out a few more low quality weeks or months. Many patients would take the same responsible view and so would their gps and oncologists. NICE should trust the patient and his medical advisers.
Section 2 (The technology)	I worry that NICE is using me, and those like me, as disposable in their attempts to bring pressure on the makers to reduce the cost of the drug. Will the situation be any different when the next drug becomes available or, like Astra Zeneca, will the source of new treatments dry up. NICE cannot expect improvements to come out of the blue. Abiraterone is obviously not a perfect solution but research proceeds incrementally, and experience gained from the use of abiraterone would provide ideas and funds for further research.
Section 3 (The manufacturer's submission)	I have no comment on this aspect
Section 4 (Consideration of the evidence)	Cost benefit analysis of the kind referred to is very difficult to do without ignoring longer term issues which are much harder to quantify. NICEs approach is crudely short-term.
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No comment

Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Cost, isnt it shamefull that even though the committee recognised the effectiveness patients will still be denied the drug. Once again it comes down to what is a life worth. For men to die knowing that there is a drug that could have given them more time is cruel. As a prostate cancer nurse in the NHS I am ashamed at this decision.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I was diagnosed with metastic prostrate cancer in early December 2011. After many weeks of consultation and treatment I have agreed to enter into a randomised clinical trial. I was told that I would be given one of four different drugs which are being tested for the treatment of my illness. I was chosen to take Abiraterone along with steroid tablets. The treatment/trial is due to run for two years starting today 3rd February 2012. I am most concerned that NICE are considering not allowing the drug to be used for cost reasons. I have heard many reports saying that the drug could be a breakthrough in the treatment of prostate cancer. When you are diagnosed with any sort of cancer it is a terrible shock and nothing can prepare you

	for it. I wish to object to NICESs approach to this new drug. Any feedback would be appreciated in this very worrying time. Newcastle-under-Lyme, Staffordshire.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1.1 I would strongly argue that treatment with Abiraterone should continue until it has been fully clinically trialed. How will there ever be a solution to this disease if people who are prepared to go through a clinical trial are not allowed the time to complete the treatment. 1.2 I am in full agreement that the drug should be allowed to be used at the discretion of the consultant clinician.

Role	Carer
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I object to the decision on the folowing grounds The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects, * No alternative treatments available, the alternative is death.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I contracted prostate cancer 10 years ago at the age of 55.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	as a patient with prostate cancer who has survived for 10 years with the help of the Royal Marsden I am disappointed that the appraisal committee has rejected this drug on such flimsy grounds. I was diagnosed with PC at the age of 55, due to Royal Marsden,s efforts on a clinical trial I am still alive, I have not cost the benefits system one penny and I am still leading an almost normal life. The extra cost of this drug above the threshold £50,000 has been badley assessed an smacks of manipulation of the figures. Please reconsider the facts, rassess the long term benefits of this drug to younger men like myself and treat this drug on the basis that so far no one on the original trial has died to date and if introduced now the benefits could outweigh the costs which will reduce as well. The pain control element will also reduce palliative costs well above the "extra costs" of the drug

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1	I think the decision by NICE is short sighted as the treatment prolongs life.Men

(Appraisal Committee's preliminary recommendations)	should be entitled to the same access to drugs that prolong life as women with secondary breast cancer.
Section 2 (The technology)	The cost seems to be a factor with the decision by NICE not the safety of the treatment.
Section 3 (The manufacturer's submission)	The manufacturer has made a convincing case for this treatment.
Section 4 (Consideration of the evidence)	Some men have obviously benefitted from the treatment and it should be readily available.
Section 5 (Implementation)	National decision would be welcome.
Section 6 (Related NICE guidance)	More research would be welcome but is this urgent enough?
Section 7 (Proposed date of review of guidance)	Review should be sooner rather than later.

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 horrified that NICE has come to this conclusion. All men with prostate cancer should have the opportunity to have this drug at a stage decided by their doctor as it has been shown to reduce pain and prolong life. Men should have the same opportunities for suitable drugs as women with breast cancer.
Section 2 (The technology)	The cost of this drug is what is deciding that NICE should not recommend its use. Drugs for breast cancer can be equally expensive and men should have the same oppprtunity to receive suitable drugs for their condition.
Section 3 (The manufacturer's submission)	Unfortunately this is too complicated for a lay person like myself to understand. I do know that I am concerned that there is not a level playing field for prostate cancer v breast cancer and while cost is important I or one would be willing to pay more NI togive all people with cancer better drugs.
Section 4 (Consideration of the evidence)	Evidence from patients who have received this drug demonstrate how successful they consider it to be. I feel that this should be given more weight that appears here.
Section 5 (Implementation)	We do not want a post code lottery for this drug. It needs to be available nationally.
Section 6 (Related NICE guidance)	
Section 7 (Proposed date of review of guidance)	this technology needs reviewing more quickly as men are dying while it is considered

Role	Patient
Other role	Leader of a patient group
Location	England
Conflict	no
Notes	potential user of Abiraterone
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Disagree with 1.1 Agree with 1.2
Section 2 (The technology)	The cost of drugs often goes down after some years regular usage. Sadly drug companies need extensive research investment. There needs to be continuing research into drugs to assist all patients. Prostate Cancer has been a poor relation for many years. I had hope that I would get this drug if the Docetaxol failed
Section 3	This gives a good case for deeper consideration for use of the drug.

(The manufacturer's submission)	It is a matter of the use of statistics. If men can get improved Quality and life extension this is very important. Hope is important too.
Section 4 (Consideration of the evidence)	An important consideration with prostate cancer is dealing with pain. The evidence points to a batter QAL with less pain.Extension of life given are averages, some men will have extra months or years on top of this. We are talking about last chance saloon. We have already seen the death of Mike Lockett refused abiraterone, he failed to be given this chance. Some men will be able to continue useful employment, meaning no benefit implications in those cases. The administration of the drug is simple and doesnt need expensive hospital visits. Additionally few side effects are reported.
Section 5 (Implementation)	Thanks for this information
Section 6 (Related NICE guidance)	This gives a new hope, but I gather there are some cardiac implications. Personally Id rather go with MI than a lingering PCa death
Section 7 (Proposed date of review of guidance)	Thanks for this information

Role	Patient
Other role	Prostate Cancer support group committee member
Location	England
Conflict	no
Notes	I have had a radical prostatectomy for prostate cancer
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is a very successful drug which is proven to work and should not be withdrawn. Please see my response to section 4.
Section 4 (Consideration of the evidence)	* Abiraterone has the potential to increase life by years. Not just 4 months. On the 9 month trial, nobody on Abiraterone died. Men on the placebo arm of the trial started to die after 5 months. * The drug helps men to keep in employment and not have to claim benefits because of ill heath, thus saving the government money. * Patients on Abiraterone have a greatly increased quality of life with much reduced pain. * It is very easily (and cheaply)administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects. * No alternative treatments are available, the alternative is death.
Section 5 (Implementation)	This guidance is a serious mistake.
Section 7 (Proposed date of review of guidance)	The evidence should be reviewed again immediately.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I am 62 years old. I was diagnosed with prostate cancer when I was 56. Currently my PSA levels are low and stable and I do not require treatment.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	There are no alternative drugs to abiraterone for the treatment of men with advanced cancer that has progressed beyond the stage of a docetaxel-containing regimen. By its decision, NICE is refusing men with terminal cancer access to the only drug that is available. The trial shows that abiraterone extends the life of men by at least 4 months. The

	extension of life is probably longer than 4 months because the trial only lasted 9 months and men who were on abiraterone did not die during that period, whereas men who were on the placebo arm of the trial started to die after 5 months. Abiraterone results in a substantially increased quality of life with much reduced pain. Abiraterone is very easily administered it is simply a matter of taking four tablets per day. Abiraterone has few side effects and, in the case of the person that I know who is taking the drug, abiraterone has literally no side effects. Taken together, these points show that men of a working age who are taking abiraterone could continue to be in active employment, earning a wage rather than relying on state benefits. Men who are refused abiraterone will have a lower quality of life and will die sooner.
Section 4 (Consideration of the evidence)	The use of psuedo-mathematical calculations should not be used to justify pre-determined conclusions. Prostate cancer patients have already seen erroneous calculations being used by the National Screening Committee to deny prostate cancer screening for men. NICE has approved the use of equivalent drugs for women suffering from Breast Cancer. If there is a level playing-field then end-of-life cancer drugs should be made available for men with prostate cancer in the same way that they are made available for women with breast cancer.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 2 (The technology)	i think the cost of the drug is excessive and that Janssen should be persuaded to reduce the price.It is a disgrace to judge how long this drug can extend life by on averages as in some cases this will well exceed the average,this decision could deny some patients years not months and lets face it in the cases where it does not work well then the patient would only be receiving the drugs for a few months which would hardly be a strain on the health service budget.Quite frankly a lot of cancer patients have worked all there lives and paid into the system as i have for 35 years and the thought of being told somtime soon that i might be refused a lifesaving drug sends me cold and the people making this decision should be ashamed of themselves and so should the drug company wishing to charge these astronomical prices.
Section 5 (Implementation)	If the committee are to turn down drugs that can extend life then what is the point of fundraising for cancer research and indeed the rearch itself.I would urge the committee to reconsider and approve Abiraterone.Please put yourself in this postion,sitting in a consulting room and being told your life will end in three months,your wife is sat beside you distraught and the drug that could help you is not available because it is too expensive,please try and imagine what this must be like then imagine it is the one you love thats going to die,then approve this drug.

Role	Patient
Other role	
Location	England

Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a prostate cancer sufferer I would like to comment on the preliminary recommendations. I was diagnosed with prostate cancer in 2009 and had a radical prostatectomy in an attempt to halt the disease. Unfortunately the margins were positive, meaning I have an increased risk of the disease progressing, but so far so good. I am very grateful for the treatment I have received from the NHS, and I am glad to be alive. The reason I am so disappointed with the recommendation is this. When currently available treatments no longer work, death can follow quickly. Suddenly the disease can become terminal, but after living with the disease for years, this can still come as a bit of shock. It would be great to know that although ones disease has suddenly become terminal, that there would at least be some time to get accustomed to the idea, and get ones affairs in order. The drug Abiraterone seems to provide that precious time. Please reconsider.

Role	other
Other role	Patient & Chair of The West Wales Prostate Cancer Support Group
Location	Wales
Conflict	no
Notes	I understand that some Local Health Boards in Wales have already agreed to requests to fund abiraterone. Other Local health Boards have refused funding. There is no cancer fund in Wales therefore Welsh prostate cancer patients are likely to be disadvantaged by this decision
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am very disappointed by this preliminary recommendation. I understand that in trials the drug was found to extend life whilst improving the quality of that life and is apparently well tolerated
Section 2 (The technology)	Abiraterone appears to stop the production of testosterone wherever it is being produced in the body. It therefore succeeds when other hormone therapies have ceased to be effective
Section 3 (The manufacturer's submission)	I understand that NICE has ruled out the use of this drug on the ground of cost not on the grounds of efficasy. This would appear to be a very useful drug when opportunities for the treatment of metastatic prostate cancer are otherwise very limited.
Section 4 (Consideration of the evidence)	Regrettably as there is no screening programme for prostate cancer and no symptoms for localised cancer, it is inevitable that many men are diagnosed with advanced and incurable disease. Abiraterone must be reconsidered as an end of life treatment and an important new option for these men
Section 5 (Implementation)	In Wales, the use of abiraterone has the addition hurdle of being considered by the All Wales Medicines Strategy Group. If this group follows the recent NICE decision it is unlikely, in the current economic climate that Local Health Boards will agree to its funding. Patients in Wales will therefore be denied this drug when patients in England can continue to receive funding via the national cancer fund.
Section 6 (Related NICE guidance)	None
Section 7 (Proposed date of review of guidance)	None

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

Section 4 (Consideration of the evidence)	The sentence the this guidance repeats several times is, "The Committee concluded that the evidence demonstrated that abiraterone was an effective second-line treatment for castration-resistant metastatic prostate cancer." The problem is therefore, at what price would the committee consider abiraterone cost effective?

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Why ask the public to fund Cancer Research when with research you come up with a cure like Abiraterone and then refuse it to the men who need it you are condeming them to death, earlier than necessary

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I feel that extension of life, improved quality of life and better pain relief are sufficient reasons to support the use of this treatment. It goes beyond just being palliative unlike other available options. The broad base of the testing - multinational and in numerous centres - suggests there is reliable evidence for the success of this treatment. There seems significant weakness in interpreting the data to suggest it only prolongs life for 4 months. As someone under 60 who has the disease, prolonging life seems important to me - it isnt just a disease of old men towards the end of their life expectancy. As a cancer with a poor early diagnosis rate (as in my case) it is surely fair to improve the treatment of advanced stage sufferers.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should be available to all for as long as it gives benifit
Section 2 (The technology)	Cost to nhs should take into account the savings in people benifiting from this drug not needing as much care or finacial support from the state
Section 4 (Consideration of the evidence)	The evidence is that this drug helps to improve quality of life and life exspectancy. Some people will benifit more than others but that deos not alter the fact that everyone gets some benifit from it.
Section 5 (Implementation)	The more the drug is used the more likely the price will be able to be reduced
Section 6 (Related NICE guidance)	Nice guidence should consider the patient more
Section 7 (Proposed date of review of guidance)	Should be reveiwed earlier

Role	Patient
Other role	
Location	Wales

Conflict	no
Notes	it is most important that this drug is available in wales not only in england, as we all contribute in taxes etc. the the same as england
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	it should be given to who needs it in wales
Section 2 (The technology)	cost should not be a factor
Section 3 (The manufacturer's submission)	what is money
Section 4 (Consideration of the evidence)	who has the right to put a price on life even short existance
Section 5 (Implementation)	money can be found for most things but why not this

Role	Public
Other role	
Location	England
Conflict	no
Notes	I think this drug should be availablr for sufferers of Prostate Cancer
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Disagree if the ciinician decides it would be beneficial to the patient it should bec made available
Section 2 (The technology)	Abitaterone should be available
Section 3 (The manufacturer's submission)	Agree
Section 4 (Consideration of the evidence)	Should be up to clincition

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I wish to express strongly my concern at the decision of NICE not to fund the prescribing of Abiraterone in advanced prostate cancer. I am concerned at how you have assessed increased survival attributable to Abiraterone. You rely heavily on the data from a relatively short trial while all the indications are the potential for life prolongation is much greater than this. You also appear to have hugely over-estimated the number of men who would end up receiving this medication giving abiraterone only after failed chemotherapy will significantly limit the number of men eligible for it - I am no researcher but I hear the realistic figure is around 7000 patients per year. However my greatest concern lies with NICEs contribution to how we treat patients like me, the abandoned middle aged men condemned to the loss of decades of useful life due to their bad luck in contracting a cancer which ill-informed people seem to think not worth treating. I was diagnosed last year aged 53 with advanced prostate cancer. I am likely to die in my 50s. Only screening would have allowed me to be diagnosed sooner but we have come down against screening in this country. By NOT screening (and thus saving lots of money through not screening) patients like me will continue to

	emerge, too late to treat effectively and now finding, to our horror, that life prolonging treatment is being denied to us. Somehow I think if we were women our lives would not be considered so expendable. I agreed to NICE "turning down" cabazitaxel. It is, after all, just another taxane, quite toxic and very expensive. But abiraterone is a novel agent which will almost certainly gain a central role in prostate cancer management in the future. It is relatively non-toxic, an oral medication which obviates the expensive need for visits to the chemo unit for infusions. It also has impact on quality of life over and above its life prolonging effect. I support NICE. I respect the the decisions you make and consider your guidance as the gold standard for good practice. On this occasion however, I beg you to reconsider.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I wish to express strongly my concern at the decision of NICE not to fund the prescribing of Abiraterone in advanced prostate cancer. I am concerned at how you have assessed increased survival attributable to Abiraterone. You rely heavily on the data from a relatively short trial while all the indications are the potential for life prolongation is much greater than this. You also appear to have hugely over-estimated the number of men who would end up receiving this medication giving abiraterone only after failed chemotherapy will significantly limit the number of men eligible for it - I am no researcher but I hear the realistic figure is around 7000 patients per year. However my greatest concern lies with NICEs contribution to how we treat patients like me, the abandoned middle aged men condemned to the loss of decades of useful life due to their bad luck in contracting a cancer which ill-informed people seem to think not worth treating. I was diagnosed last year aged 53 with advanced prostate cancer. I am likely to die in my 50s. Only screening would have allowed me to be diagnosed sooner but we have come down against screening in this country. By NOT screening (and thus saving lots of money through not screening) patients like me will continue to emerge, too late to treat effectively and now finding, to our horror, that life prolonging treatment is being denied to us. Somehow I think if we were women our lives would not be considered so expendable. I agreed to NICE "turning down" cabazitaxel. It is, after all, just another taxane, quite toxic and very expensive. But abiraterone is a novel agent which will almost certainly gain a central role in prostate cancer management in the future. It is relatively non-toxic, an oral medication which obviates the expensive need for visits to the chemo unit for infusions. It also has impact on quality of life over and above its life prolonging effect. I support NICE. I respect the the decisions you make and consider your guidance as the gold standard for good practice. On this occasion however, I beg you to reconsider.

Role	Patient
Other role	

Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Trials have shown a high success rate in prolonging life - and a good quality life, too
Section 2 (The technology)	Cost should be a very secondary consideration
Section 3 (The manufacturer's submission)	This supports my previous contention that the drug increases healthy life expectancy
Section 4 (Consideration of the evidence)	The key phrase is life extending not merely palliative

Role	Patient
Other role	Chairman of Prostate Cancer Support Group
Location	England
Conflict	no
Notes	On behalf of the 40 members of my support group please reverse the provisional decision. Men with advanced PC desperatly need this drug - they have nowhere else to turn.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is the wrong decision.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a man involved in fighting prostate cancer for 13 years my next course of treatment is antiandrogens. As you know these give a median effective reaction of 18 months before I will become castration resistant and have very limited options available. As a 65 year old man abiraterone affords another weapon in a limited arsenal available to castration resistant outcomes. It has the proven potential to give me added years of life not the 4 months assigned to it. Men like me need this opportunity not only at that stage but preprogression with recurrence as I now find my situation to be. No-one wants to go away and die. We are fighters and need an arsenal with effective and proven cost effective treatments and limited side effects. We do not want to be told to go away on less effective means. Carrying out my own research/ reading on this and being a statistician myself I believe it can offer many men like myself many added years of life, not months. I need advances such as this in my preprogression stage as do many others. There are very limited alternatives available. This could save the NHS money in alternative treatments for those told to go away and "die"

Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	It doesn?t seem morally right that NICE would reject a drug that clearly benefits a large majority of those that have and do take it. The basis for rejection is not

preliminary recommendations)	successful treatment but cost per patient at approximately £3,000 per month. This drug will not be given to every post chemo patient just for the sake of it, its prescribed on an individual basis. Any person that has failed Docetaxel chemotherapy has late advanced disease and this may be the only possible chance for life. Four months life extension is both misleading and confusing for many of us, there are Abiraterone patients alive five years past their initial doseage.
Section 2 (The technology)	During clinical trials, reporting of all and any side effects is expected from patients and crucial for the licensing of the drug. Side effects are not offered freely but demanded from the trial doctors. Persons who are quite well and taking Abiraterone will report any symptom they suffer during the trial such as headaches, fatigue and nausea, after all they all have late advanced Prostae Cancer.... the differences between the control arm and those taking the drug do not, in my opinion, warrant rejection of funding
Section 3 (The manufacturer's submission)	I would challenge any figures that do not take humanity and the chance of life into consideration. The people that are expecting to have free access to Abiraterone are not all bed ridden. Many are active and would have 20 or more years of life if it wasn?t for their prostate cancer, every opportunity should be allowed for experts to prescribe life saving drugs when appropriate
Section 4 (Consideration of the evidence)	Experts, patients and NICE all agree Abiraterone is a good product yet NICE state that it?s too expensive to fund. Find a way around this surmountable problem, if Abiraterone is unsuccessful now, what will happen with MDV3100, TAK-700, Cabazitaxel and other significant prostate cancer drugs?
Section 5 (Implementation)	I wonder how much it costs for NICE to plan, investigate, develop and produce a report on an excellent drug only to refuse funding based on cost per person. Even the recent breast implant debacle had funding agreed, much of this was cosmetic. As a person with late advanced Prostate Cancer, I am unable to gain access to the most exciting new development in this field for many years, a British discovery, shameful

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 5 (Implementation)	As with most aspects of prostate cancer care i.e PSA /DRE screening our members find Nice results do not compare with members findings as our members had i.e no pain and over a year so far living not 4 months as Nice report.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Have recently undergone radical prostatectamy and subsequent radiotherapy - awaiting psa result. I wholeheartedly disagree with NICEs decision, and believe that it should be available to all.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Difficult to understanfd all of technicalities, but still believe it should be available to all prostate cancer sufferers.
Section 5 (Implementation)	As above.

Role	Patient
Other role	
Location	England
Conflict	no

Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This recommendation should be reversed. It is clear from evidence that the drug works. The issue is one of price.
Section 2 (The technology)	The cost is presumably negotiatable downwards longer term, and the longer term view should prevail.

Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The reasons must always be result based and not in anyway financially based
Section 2 (The technology)	All medication has some side effects and these should not be taken into consideration unless any likelyhood of general worsening of condition
Section 4 (Consideration of the evidence)	the main consideration should always be does the patient benefit from the treatment and not some obscure mathematical graph.

Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	Ive recently finished chemotherapy for metastatic prostate cancer - Abiraterone represents one of the few treatments still available to me.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone is one of the very few treatments available for metastatic castration-resistant prostate cancer. It represents the best chance currently available for maintaining a continuing quality of life. As such, it should be made available until a better or cheaper alternative appears.
Section 3 (The manufacturer's submission)	So Abiraterone works!
Section 4 (Consideration of the evidence)	The effectiveness of Abiraterone is accepted, as is its ability to extend quality life by a significant length of time. It should therefore be approved, in the absence of any realistic alternative. The financial reason for rejection poses the question what value can be placed on quality life?. Has the cost been balanced against the positive contributions that patients who are well can make to society?
Section 6 (Related NICE guidance)	Abiraterone works for longer than Cabazitaxel, is taken in the form of pills at home, and has fewer side-effects.
Section 7 (Proposed date of review of guidance)	Too long - Ill be dead by then unless Im given something as effective as Abiraterone!

Role	Carer
Other role	
Location	England
Conflict	no
Notes	Please reconsider your decision. I have seen the difference this drug makes, it allows men to keep working thus not claiming benefits, it gives them their life back - there is no alternative except death. It reduces pain miraculously and has very few side effects. Once the drug is prescribed it is self administered so no on costs

	except review
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The trial results show 100% extention of life, what can get better than that? These are not always old men (whose lives you value lightly) but younger men who can still contribute to the economy with this treatment.
Section 2 (The technology)	Cheaper than benefit payments and oncosts
Section 3 (The manufacturer's submission)	All I know is it works!

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Patient with Prostate Cancer stage 2, Gleason 6/7. Underwent external beam radiotherapy and Cyproterone/Zoladec implants 2 years ago. Currently asymptiomatic but concerned for my future. Retired Teacher of Science (Chemistry and Biology) but at my limits of understanding with your document. Here goes.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Agree with 1.2 persons should have this option.
Section 2 (The technology)	The side effects listed are survivable. The alternative is a long and painful death. A friend suffered this fate last year. I do not want this outcome to happen to any other prostate patient.
Section 3 (The manufacturer's submission)	My understanding of this section is that Abiraterone is a successful treatment. The alternative is death.
Section 4 (Consideration of the evidence)	Yes it is an expensive treatment - but it is successful, and there appears to be no viable alternative, other than giving up and waiting for a painful prolonged and avoidable death. The potential is to increase expectation of life by years not months. It is a tablet format and easy to take anywhere anytime. Few side effects. Men of appropriate age are able to stay in/ return to work - rather than face a (short) life on benefits.
Section 5 (Implementation)	I am not qualified to comment.
Section 6 (Related NICE guidance)	Should not treatment with abiraterone be available as a "treatment of last resort" until an alternative regimen becomes available.
Section 7 (Proposed date of review of guidance)	No comment.

Role	Patient
Other role	
Location	Wales
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I was dianosed with PC at age 50 some 10 years ago. I am on hormone treatment and will be so for the foreseeable future. Hoever I know that it is only a matter of time until my treatment losses its effectiveness and I will have to undergo addition treatment. Unltimately I expect to have to contend with terminal cancer and I believe that the committees recommendation is wrong. As a society we should conside ourselves obligued to make the last days/weeks/months of any terminal cancer patient as painfree and comfortable as possible. My father died after suffering severe end of life effects, partivularly bone pain, of PC for 3-4 months.

	Perhaps this treatment could have made his last months bearable. Any additional time with him would then have been a lovely bonus. If I end up in my fathers situation I can only hope that this recommendation has been reversed.

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I wish the following information to be considered during the consultation process. This drug has the potential to increase life by years not months. During the 9 months trial of this drug no patients with advanced prostate cancer taking the drug died. Placebo taking patients on the trial started to die after 5 months. Patients taking the drug can continue to work avoiding costly benefit payments and medical costs. It greatly increases patients quality of life and greatly reduces the patients pain. It is easlily administered by patients in tablet form with few if any side effects. No alternative treatments are available so refusing the availability of this drug is condemning men with advanced prostate cancer to an early death. This drug is already helping several hundred patients under the Government cancer drug funding so it is discrimatory to not provide it to patients after 2014 when this funding ceases

Role	Patient
Other role	
Location	England
Conflict	no
Notes	Prostate Cancer sufferer - diagnosed aged 49 - under long term contaiment programme - will require Abiraterone in the future
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	THis is an outrageous decision and is a virtual death senrtence to all those men sufferering with advanced prostate cancer. This drug is proven not only to prolong life but allow for a good quality of life when there is little other options. The rationale that it cannot be justified on cost terms is insulting and outrageous. I suspect that the manderins at NICE who made this dicision have not yet been affected or touched by this dreadful desease.....maybe Sir Andrew Dillon can spare some time in the future and come and personally explain to my wife and young children that his decision meant that their Dad was condemned to a premature death ? A drug that has been developed in UK, and has kept one of the worlds most notorious convicted terrorists alive for many years,and is licensed in many other developed countries is being denied to British men because of cost reasons, when millions are being spent on correcting cosmetic breast implants. An absolute disgraice and history will judge NICE in the same terms as other infamous mass murderers of history. This decision MUST BE REVERSED

Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have listened to a topic on Radio Leicester today and from that I would prefer that treatment with the drug be made available via the NHS to patients who choose this drug where they have been informed of all information.
Section 2 (The technology)	Inform patients of the possible side effects and other information and give them the choice.

Section 3 (The manufacturer's submission)	Make this information available to the patient and give the patient the choice.
Section 4 (Consideration of the evidence)	Should be available for whatever timespan to those who need it irrespective of cost having given the patient all information.
Section 5 (Implementation)	Should be available across the country for whatever timespan to those who need it irrespective of cost having given the patient all information.
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	Should be reviewed now, February 2012

Role	Public
Other role	
Location	England
Conflict	no
Notes	The importance of drugs such as this is to prolong active life when other treatments have failed. We all have a duty to support those in dire need.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	* The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain * Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects, (In my own case none) * No alternative treatments available, the alternative is death. * The potential to increase life by years. 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability keep employment and not claim benefits * Greatly increased quality of life much reduced pain * Easily administered, 4 tablets per day * Few side affects, * No alternative treatments..

Role	Patient
Other role	
Location	England
Conflict	no
Notes	I have locally advanced prostate cancer and consider this treatment as a possible future benifit
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The potential to increase life by years. Not just 4 months. On the 9 month trail, nobody on the drug died. Men on the placebo arm of the trial started to die after 5 months. Hence 4 months of extra life. * The ability to help men to keep in employment and not have to claim benefits because of ill heath * Greatly increased quality of life with much reduced pain

	* Very easily administered, just 4 tablets per day, at home (or anywhere else you may be.) * Very few side affects, (In my own case none) * No alternative treatments available, the alternative is death.

Role	Public
Other role	
Location	Scotland
Conflict	no
Notes	My father has stage 3 prostate cancer and is receiving treatment to slow the spread of the disease. I am saddened to read the decision regarding abiraterone, as one day, my father may be one of the patients who could benefit from such treatment. I urge NICE to reconsider its decision and take into account the support abiraterone has received from The Prostate Cancer Charity and Cancer Research UK. I hope my father and other men with prostate cancer will continue to receive the care and treatment they need and deserve, at all stages in their cancer. Best wishes,

Role	
Other role	
Location	
Conflict	
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I would be grateful if you would accept this email as an appeal against NICE's decision not to allow abiraterone prescription under the NHS because of cost. Apart from the ethics of disallowing a drug admitted to 'extend life' by Andrew Dillon, it is unacceptable to also disallow its special use under the 'end of life guidance' regulations as, according to CRUK, fewer than 7000 men currently will require this treatment. In addition, prostate cancer, unlike the equivalent cancer in women i.e. breast, is vastly underrepresented in terms of pharmaceutical interventions, particularly in the case of progressive castration-resistant metastatic prostate cancer. Please reconsider.

Name	Prostate Cancer Support Group (Redbridge)
Role	patient
Other role	
Location	
Conflict	
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The Prostate Cancer Support Group (Redbridge) would like to be added to your petition regarding Abiraterone "To express our members' need for NICE to reverse their decision not to authorise Abiraterone as an end of life therapy in the NHS"

	We are concerned at the decision not to fund Abiraterone as this is the hormone therapy whose trial was so successful that it reached the national press, as the hormone was so obviously beneficial that it would have been unethical to continue the UK trial. All those on the trial who had been receiving the placebo rather than Abiraterone were given the therapy. This, however, is the same end-of-life therapy which NICE has in its first consultation review refused on the basis that the cost of the "Quality Adjusted Life Years" was above their benchmark. The average benefit period is stated as 4 months but we would like this to be reviewed by NICE as we understand in the UK no-one died before the 6 month period and there are some people still living after 6 years. Why should this matter? * the average number of new cases of prostate cancer diagnosed locally is one per day * the average number of new cases of prostate cancer diagnosed in the UK is 35,000 per annum * the average number of deaths per year due to prostate cancer in the UK is 10,000 per annum Not nice! The Prostate Cancer Support Group (Redbridge)

20 FEB 2012

:aterone for castration-resistant metastatic prostate cancer previously treated with a docetaxel-containing regimen

Public Comments

note that all comments must be received at NICE by 5pm on Thursday 23 February return to: Enquiry Handling Team, NICE, Level 1A City Tower, Piccadilly Plaza M1 4BD 45 003 7781, Email: nice@nice.org.uk

	[redacted]
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:t of t with acturer?	
	AS I AM 84 YRS & SUFFERING FROM PROSTATE CANCER I HAVE PAID NATIONAL HEALTH ALL MY LIFE, NOW THERE IS A NEW DRUG ABIRATERONE IF IT IS BENEFICIAL TO ME I CAN'T UNDERSTAND WHY I CAN'T HAVE IT FREE ON THE NATIONAL HEALTH SERVICE. MY PRESENT DRUG PRESCIBED IS DIETHYLSTILBESTROL 1 MG - 3 TIMES A DAY
ents on individual sections of the ACD:	
ı 1 Committee's y ıdations)	YOUR COMMENTS WOULD BE APPRECIATED MANY THANKS. K. BLOODWORTH MR.

21 FEB 2012

Abiraterone for castration-resistant metastatic prostate cancer previously treated with a docetaxel-containing regimen

Public Comments

Please note that all comments must be received at NICE by 5pm on Thursday 23 February
Please return to: Enquiry Handling Team, NICE, Level 1A City Tower, Piccadilly Plaza M1 4BD
Tel: 0845 003 7781, Email: nice@nice.org.uk

Name	[redacted]
Role	PATIENT
Other role	
Location	[redacted]
Conflict of interest with manufacturer?	NONE.
Notes	I was prescribed ABIRATERONE at Christmas 2011 and already experiencing an IMPROVEMENT in my well being and overall health. Although the drug is expensive the hope for a increased life span and a optimistic view for close relatives, in my view these make the drug very important.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Apparently the Lockerbie Bomber was prescribed ABIRATERONE and is STILL going after 3 years! Compared with what the NHS spend on Laxatives and wastages the cost of this drug in my view should not be the criteria in deciding its use Please NICE reconsider your decision. How may member on the NICE Committee have advanced PROSTRATE CANCER with the threat of shortening their lives? [redacted]

22 FEB 2012

Abiraterone for castration-resistant metastatic prostate cancer previously treated with a docetaxel-containing regimen

Public Comments

Please note that all comments must be received at NICE by 5pm on Thursday 23 February
Please return to: Enquiry Handling Team, NICE, Level 1A City Tower, Piccadilly Plaza M1 4BD
Tel: 0845 003 7781, Email: nice@nice.org.uk

Name	[redacted]
Role	PATIENT
Other role	[redacted]
Location	[redacted]
Conflict of interest with manufacturer?	NO
Notes	WHY HAVE THE WALES MEDICINE STRATEGY GROUP HAVING CONSIDERED THE SAME EVIDENCE APPROVED USE. THIS SEEMS TO MAKE YOUR DECISION EVEN MORE UNREASONABLE
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	See over

Section 2 (The technology)	
Section 3 (The manufacturer's submission)	

Q HAS THE RELEVANT GUIDANCE BEEN TAKEN INTO ACCOUNT

Section 4 (Consideration of the evidence)	YOUR 48 PAGES COMPLETELY IGNORE THE WORD COMPASSION FOR PROSTATE CANCER SUFFERERS WHO ARE HORMONE RESITANT CABAZITAXEL AND ABIRATERONE OFFERED SOME HOPE BEYOND DOCETAXEL CHEMOTHERAPY. YOUR DECISIONS LEAVE A BLEAK OUTLOOK FOR PEOPLE LIKE MYSELF. MY OWN JOURNEY HAS LASTED FOR
Section 5 (Implementation)	17 YEARS (PRESENT MEDICATION DEXAMETHASONE 500 MOO AND ZOLADEX QTLY INJECTION). YOUR DECISION MAKING SEEMS COMPLETELY TO IGNORE THE FACT THAT THESE DRUGS CAN MAKE LIFE
Section 7 (Related NICE guidance)	MORE TOLERABLE DURING THE FINAL MONTHS OF LIFE. ABIRATERONE CAN AND DOES IN SOME CASES WORK FOR YEARS RATHER THAN MONTHS.
Section 8 (Proposed date of review of guidance) NB: The review date is the date when NICE will consider whether to reappraise this drug.	THE ATTACHED ARTICLE IN THE DAILY MAIL RECENTLY DETAILS THE HARROWING EXPERIENCES OF RELATIVES FORCED TO WATCH PROSTATE CANCER VICTIMS DYING WHEN THE
Date 17/2/2012	TECHNOLOGY DOES EXIST TO HELP!!

WHAT IS THE POINT OF DRUG TRIALS IF THE MAJORITY ARE DISMISSED SO SUMMARILY [redacted]

THE RT HON DAVID WILLETTS MP

HOUSE OF COMMONS

LONDON SW1A 0AA

Tel: 020 7219 4570
Fax: 020 7219 2567

16 FEB 2012

Professor Sir Mike Rawlins,
Chair,
NICE,
Mid City Place,
71 High Holborn,
London WC1V 6NA

15th February 2012

Dear Mike,

I enclose a letter from my constituent [redacted]

Mr. Cutbill suffers from prostate cancer and has been successfully treated thus far by Abiraterone which he has obtained on his medical insurance which has now run out. I understand that NICE is currently considering whether to make this drug available on the NHS, and whilst I recognise the many different factors NICE must take into account I hope that the success of my constituent's treatment may be of some use in your deliberations.

Yours sincerely

David Willetts

THE RT HON DAVID WILLETTS MP
(Encl)

WORKING FOR HAVANT

Email: willettsd@parliament.uk
Website: www.davidwilletts.co.uk
Constituency Office: 19 South Street, Havant, Hants PO9 1BU
Tel: 023 9249 9746 Fax: 023 9249 8753

[redacted]

David Willets MP
House of Commons
Westminster
London
SWIA OAA

Dear Mr. Willets,

NICE Abiraterone

I have prostate cancer and have recently been prescribed Abiraterone by my consultant. The results are outstandingly good but my medical insurance has run out.

NICE (0845 003 7780) are currently considering whether or not this drug should be available on the NHS. I am appalled to think that it will not be accessible to all those who would benefit from it.

I would be grateful if you would contact them on my behalf to urge them to agree to the availability when they meet later this month. Alternatively, could you arrange for me to continue my current medication under the NHS?

I look forward to hearing from you.

With thanks,

Yours sincerely,

[redacted]

[redacted]

Mr Jeremy Powell
Project Manager
National Institute for Health and Clinical Excellence
MidCity Place
71 High Hollborn
London
WC1V 6NA

16th February 2012

Subject - Abiraterone Appraisal Consultation

Dear Mr Powell,

I understand that Abiraterone has been rejected by NICE for treatment of CRPC and is consequently not available to NHS patients. Since this drug has been proven to be successful and has already been approved by the USA FDA, Canada Health and European MA, such a decision by NICE is difficult to understand.

I also understand that the Abiraterone trial involved 1195 patients from 13 countries and resulted in 50% of patients on the drug surviving more than 14.8 months. The comparative figure for patients on the placebo was only 10.9 months. Thus for 50% of men the actual life extension will be longer.

What is as important is that the drug is easily administered by patients in their own home and it gives an increased quality of life with reduced pain and moderate side effects. There are no alternative treatments.

As a prostate cancer patient I am concerned that a drug that has been proven to work is being rejected solely because of the costs involved of c.£3000/month. Given that probably less than 20% of all prostate cancer patients identified each year will suffer from CRPC, the cost involved in approving the drug for the NHS will be c.0.3% of the overall NHS budget and I urge NICE to reconsider their decision.

Yours sincerely,

[redacted]

[redacted]

Mr Jeremy Powell,
Abiraterone Technology Appraisal
Project Manager,
N.I.C.E.,
71 High Holborn, WC1V 6NA.

Dear Mr Powell,

ABIRATERONE.

On 2nd February 2012, N.I.C.E. stated that it did not recommend the use of Abiraterone in the N.H.S. I am most concerned by this decision, having been diagnosed with Prostate Cancer 12 months ago.

You have already declined Cabozitaxel, and I therefore hope that this decision can be reversed — it would even then be the only new drug authorized to combat this condition. It is highly successful, and long lasting, being easily administered, with minimal side-effects.

It gives sufferers like myself great hope for the future — it really must be passed for use by the N.H.S..

Yours truly,

[redacted]

[redacted]

TO MR JERIMY POWELL
ARBIRATERONE APPRAISAL
PROJECT MANAGER,
NATIONAL INSTITUTE FOR HEALTH, 10.1.2012.
AND CLINICAL EXCELLENCE,
MID CITY PLACE,
71 HIGH HOLBORN,
LONDON.
WC 1V 6NA
10TH JANUARY 2012
SUBJECT: ARBIRATERONE APPRAISAL CONSULTATION,
DEAR MR POWEL,

I AM IN THE LATE STAGES OF PROSTATE CANCER WHICH HAS SPREAD TO MY BONES AND SPINE,

WITH GREAT INTEREST I HAVE READ ABOUT THE DRUG ARBIRATERONE. THIS DRUG HAS BEEN SHOWN IN A RECENT TRIAL TO GREATLY INCREASE THE QUALITY OF LIFE OF PATIENTS SUCH AS MYSELF BY GREATLY REDUCING PAIN, IT ALSO HAS VERY FEW SIDEEFFECTS, IT CAN BE TAKEN AS FOUR TABLETS THUS REDUCING THE COST TO NHS.

I AM SHOCKED AND DISMAYED THAT THIS DRUG WHICH HAS SO MUCH TO OFFER FOR THIS DISEASE HAS BEEN REJECTED BY N.I.C.E.

PLEASE REASSES YOUR DECISION WITH THE ABOVE POINTS IN MIND

YOURS SINCERY,

[redacted]

[redacted]

Mr Jeremy Powell,
Arbiratorone Technology Appraisal Project Manager,
National Institute for Health & Clinical Excellence
Mid City Place, 71 High Holborn,
London, WC1V. 6NA.

12th February 2012.

Dear Mr Powell,

Arbiratorone

I am a Prostate Cancer patient and am very concerned that NICE feels it cannot authorise the use of the above drug by the NHS.

It has the potential to increase life by years not just 4 months & during the 9 month trial nobody on the drug died.

It can assist men to keep in employment with an increased quality of life & few side effects. Also it is very easy to administer in tablet form & would not require attendance at hospitals.

The drug has been shown to work although the initial cost is large this would no doubt reduce with greater use - & in any case NICE to not seem to have set against the cost the fact that patients could administer the drug themselves in tablet form.

I request that NICE reverse their decision & licence the drug for general use where it is clinically appropriate.

With thanks for your further consideration,

Yours faithfully,

[redacted]

Recd
14/02/12

[redacted]

7 February, 2012

Mr. Jeremy Powell
Abiraterone Technology Appraisal Project Manager,
National Institute for Health and Clinical Excellence.
Mid City Place
71 High Holborn,
London, WC1V 6NA

Dear Mr Powell,

How heartening to hear that Abiraterone may be of significant assistance to those suffering from advanced prostate cancer, but how disgracefully disappointing it will be if the (unelected/undemocratic?) NICE panel deem it is too expensive for general use.

We spend £Billions on Bankers any ways, but money spent to save any human life is a step too far? I hope not.

Yours sincerely,

[redacted]

[redacted]

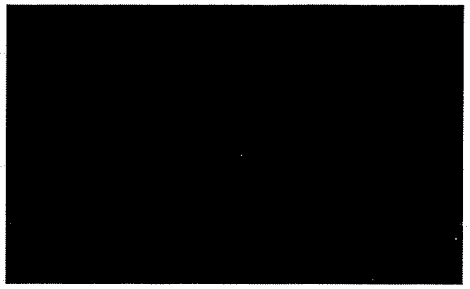
12th FEB. 2012

Dear Ms Powell

It is inconceivable to think that something that has been proven to extend someones life is not approved. Surely it must be in the interest of the NHS to help pain relieve and extend the life of a person who can work and pay taxes instead of being on sick-pay as well hospital treatment. So please approve Abiraterone for treatment for your sake and ours! A prostate cancer patient

Yours sincerely

[redacted]



MR JEREMY POWELL
ABIRATERONE TECHNOLOGY APPRAISAL PROJECT MANAGER.
NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE
MIDCITY PLACE
71 HIGH HOLBORN
LONDON
WC1V 6NA.

15TH FEBRUARY 2012

SUBJECT - ABIRATERONE APPRAISAL CONSULTATION

Dear Mr Powell

I have read that Abiraterone has been rejected by NICE and therefore will not be available to NHS patients. I find this hard to understand as it is a very successful drug which has been proven to work.

It has the potential to increase life by years, not just 4 months. During the 9 months trail nobody on the drug died. Men on the placebo arm of the trail started to die after 5 months, Hence the quoted 4 months of extra life, this seems to be misleading as the as the actual life extension will prove to be much longer.

It gives a greatly increased quality of life with much reduced pain and has very few side affects. There are no alternative treatments available; the only alternative is no treatment and death.

Mr Powell as a prostate cancer patient and a person who has had dealings with the Big C I pray to God that neither you or your team never have the misfortune to have dealings with cancer, as I have. To have your Beloved, mother of your children, given ~~or~~ two weeks to live. and four days later sit and watch Her slip into a comatose faint for 10 hours twitching and

moaning in agony of the pain that cancer causes before it finally takes your life at the age of 42.

As previously stated I am a Prostate Cancer patient, I am obviously very worried that a drug that has been proven to work on prostate cancer and has the ability to help men to keep in employment and not have to claim benefits because of ill health. It is very easily administered just 4 tablets per day at home or (anywhere else you may be) this must reduce the overall cost to the NHS. and benefit system.

It is a devastating outcome that the drug that could help thousands of prostate cancer patients live is not being accepted due to the cost involved.

NICE do not appear to have taken into account the fact that the drug is administered at home by the patient and that the costs of the treatment will reduce over the life of the drug.

I ask that NICE reconsider their decision to reject Abiraterone and instead licence the drug for general use where considered clinically appropriately without further delay and putting a lot of worried mens minds at rest

[redacted]

[redacted]

[redacted]

Dear Mr Powell

ABIRATONE APPRAISAL CONSULTATION

As someone who has been fighting Prostate Cancer eight years I am very disappointed at the decision taken by NICE not to approve the drug.

I have read how successful it has been for those it has been prescribed for and am very sad to realize that if and when I come to a later stage in my fight against PC that this will be an option for me - due to this decision

I accept fully that there is a need to cut costs in this period but feel that life extending/improving drugs should not be so readily rejected.

It is a terrible decision that NICE has taken.

Regards

[redacted]