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

Role	[redacted] TACKLE
Other role	
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Notes	Dear Mr. Powell The original ACD – October 2013 – contained the statement that: **"Enzalutamide is recommended as an option for treating hormone-relapsed** **metastatic prostate cancer in adults, only if:** *** their disease has progressed during or after 1 docetaxel-containing chemotherapy regimen and * the manufacturer provides enzalutamide with the discount agreed in the patient access scheme."** In January 2014 a FAD was issued – containing the statement **"Enzalutamide is recommended as an option for treating hormone-relapsed metastatic prostate cancer in adults, only if:** **• their disease has progressed during or after docetaxel-containing chemotherapy and they have not had treatment with abiraterone and** **• the manufacturer provides enzalutamide with the discount agreed in the patient access scheme."** It contained for the first time a caveat that the person had not had treatment previously with Abiraterone. This was a clear case of procedural failure on NICE's part. The FAD was with drawn and we were requested to delete it. It was all a bit 1984ish. Later in January 2014 a new ACD was issued requesting comments but with the above statements verbatim contained in the withdrawn FAD. This has caused a great deal of adverse reaction from both clinicians and patients. There is a way out of this situation. It is a temporary compromise until facts can be established as to whether treatment of Enzalutamide is effective after Abiraterone with a sizeable cohort. The compromise is around the word "treatment"; there are a number of patients having to be taken off Abiraterone early after a month or so because of the adverse effect of the drug on their liver. They therefore cannot be said to have had treatment by Abiraterone as it never went to the full course when the disease progressed. The caveat could thus be amended to read: **"their disease has progressed during or after docetaxel-containing chemotherapy and they have not had the full**

	course of treatment with Abiraterone" As I said earlier it will not please everyone but in the fullness of time more work could be undertaken to examine whether Enzalutamide would be effective after the full course of treatment by Abiraterone. I would ask that my proposal is given serious consideration but I would like to stress that this is a personal opinion and has not been endorsed by the Prostate Cancer Support Federation [redacted]

Role	[redacted] South Warwickshire Prostate Cancer Support Group
Other role	Retired
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Notes	I am writing in my capacity as [redacted] South Warwickshire Prostate Cancer Support Group. The group met this afternoon and there was great concern expressed about the change in NICE rules about use of Enzalutamide that were published this week. There are members of our group on Abiraterone and this has obvious consequences for them but is of concern to all our members who live with prostate cancer and know that their current treatment may cease to be effective in the future. Our objection and indeed confusion arises from the mixed messages being sent out by NICE on this issue. When NICE approved Enzalutamide in October 2013 it was without any restriction about it being offered to men who had been treated with Abiraterone. Then in January the final document included this restriction. As I understand it NICE then received protests that this broke the due process rules. NICE then cancelled the FAD (Final Appraisal Determination) and asked everybody to delete it from their computers and pretend it never existed. You have now issued this ACD (Appraisal Consultation Document) with the restriction included. Confusing or what? In passing Enzalutamide for use in this way NICE has effectively made it unusable, because at the moment, most people who need Enzalutamide have been on Abiraterone. I have a friend who has been on Enzalutamide now for 14 months (after Abiraterone) and apart from some fatigue he is very well indeed. I think this speaks for itself and I very much hope that NICE will take these issues to heart and do the right thing by reverting to the guidance originally provided in

	October 2013.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As someone who lost their father to prostate cancer over 12 years ago when treatment options were even more limited, it is so good to see new developments such as enzalutamide. Given that the options are still very limited, in my opinion it is vital that men at this advanced stage and their families, are not subjected to distressing restrictions but are offered all treatment which is suitable and relevant to them.

Role	other
Other role	Patient's relative
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My father was diagnosed with incurable prostate cancer in December 2012. For what seemed like a very hopeless situation I have continued to be surprised by the options that have been available to him. Just before Christmas 2013, my father attended the hospital for an appointment with his oncologist where he was given the news that not only would he be having his next session but would also be starting a new drug (Enzalutamide) after his chemotherapy sessions had finished. We were all delighted, and this news surpassed all expectations any of us had. My father had read about this drug and was so pleased. We all had a bit of hope. My father, prior to starting his chemotherapy cycle (Docetaxel) was given Abiraterone for approximately three months. He learnt by reading a newspaper article that because of this he will not be eligible for Enzalutamide and at his next appointment with his oncologist, the bad news was confirmed. I have spent a great deal of time reading as much as I can about this draft advice from the beginning i.e. when there was no mention of the Enzalutamide not being available to men who had previously had Abiraterone to the current article on the NICE website ?Behind the Headlines - Prostate cancer drug decision a "cruel twist??. The article promotes the fact that there are more people being offered this i.e. the patients who have had more than one round of chemotherapy but doesn?t seem to admit that for the people on Abiraterone there has been a change of mind. My Father was given hope and then it was taken away. Believe me this is a very cruel twist for, my family, me and of course my Father and others in the same situation so please don?t believe there isn?t a cruel twist for

	some people. I very much understand the need to make difficult decisions based on financial reasons and if this is a financial decision, why was this caveat not included from the beginning. If it isn?t a financial decision but because of a safety concern, or lack of information, why is there not the same concern for Scottish men. I understand that the SMC have added no such caveat? I don?t understand why this caveat wasn?t included in the beginning. It is worse to believe something and then have it taken away than to never have been given the belief at all and this is what I am most angry about. I have been considering getting the money together to try and register my father as a private patient with his consultant so he would be able to have a chance with this new drug. Would I be wasting my money? Can you answer why this decision has been made as the best explanation I could find is the one below which is very vague. However, the Committee was aware that patients in this subgroup in AFFIRM had not received previous treatment with Abiraterone and the Committee had not seen evidence about the sequential use of Abiraterone and Enzalutamide. Because of this, the Committee agreed that the evidence it had considered for the subgroup could not be generalised to patients who had previously received Abiraterone. Why had the committee not seen this evidence? Have they subsequently seen any evidence? Can I get any evidence or have you details further reading? Have the SMC considered any evidence? To summarise, I am so disappointed that this option has been closed to my Father and others like him but I wish more that it had never been talked about in the first place and then quickly removed without many answers at all. I urge you to reverse this cruel decision, give us some hope back and my Dad a chance for a bit of a longer life.

Role	other
Other role	Patient's friend
Location	England
Conflict	no
Notes	I am shocked and dismayed at the decision to not allow men who have had Abiraterone have Enzalutamide. Why is it ok in Scotland and not England? I do not understand it. My friend is desperate for a chance to try this drug, what else is there for him to try? Please change your mind on this ? it just might give him more time with his family, especially his grandchildren ? every day counts. You can make a difference - please make it. Thank you.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	I am shocked and dismayed at the decision to not allow men who have had Abiraterone have Enzalutamide.

preliminary recommendations)	Why is it ok in Scotland and not England? I do not understand it. My friend is desperate for a chance to try this drug, what else is there for him to try? Please change your mind on this ? it just might give him more time with his family, especially his grandchildren ? every day counts. You can make a difference - please make it. Thank you.

Role	Public
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Restriction does not apply in Scotland. Second-class treatment for England. Men should have the option to choose.
Section 2 (The technology)	There is evidence that Enzalutamide takers live longer than those who don't take it. Wider use is essential to establish whether the technology works on a broad sample base.

Role	Carer
Location	N Ireland
Conflict	no
Notes	My husband was diagnosed with advanced metastatic disease exactly six years ago and has taken part in two clinical trials, though not of this particular drug. What is the point in men volunteering if NICE subsequently decline the drug, often when it is available privately to those who can afford it or have access to local funding such as the Cancer Drugs Fund for England
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Many men have waited for Abiraterone and for some it has been brilliant but for others like my husband it had no effect at all. The trials show that a significant minority of men failing Abiraterone will still benefit from Enzalutamide so we should at least allow them to try it
Section 2 (The technology)	Easy drug to administer, price on a par with Abiraterone
Section 3 (The manufacturer's submission)	If men don't respond to Enzalutamide it will become obvious very quickly and treatment stopped, thus saving money.
Section 4 (Consideration of the evidence)	Excluding men that have had / failed Abiraterone is a huge mistake and extremely unfair as this is the path many will have been guided down under previous advice. The current situation places an undue decision burden on men who already have difficult choices to make!
Section 5 (Implementation)	Discriminates against a "significant" minority
Section 7 (Proposed date of review of guidance)	2015 is far too far away when one man dies every hour from this disease
Section 8	no comment

(Appraisal Committee members)	

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The decision you have made to prevent men accessing enzalutamide, if they?ve previously had abiraterone is extremely unfair and heartbreakingly disappointing. Especially as this seems to be a very cruel u-turn on the part of NICE, since we were led to believe this was not going to be the case according to your original draft decision. My Dad has advanced prostate cancer and very sadly he is now running out of treatment options available to him. I am not ready to loose my Dad, and he is not ready to leave me. You have the power to potentially give us the chance to spend some more precious, precious time together. Ultimately this decision means life or death for my Dad. I am an only child and my Mum is also recovering from cancer, and I am a carer for them both. You have no idea how excruciatingly difficult it is to be in this situation. I?m desperately hoping that you will reconsider your decision, to give hope to my Dad, me, and other men and families who find themselves at this horrifically soul destroying crossroads. PLEASE SEE MY OTHER COMMENTS UNDER POINTS: 3, 4 AND 6.
Section 3 (The manufacturer's submission)	The company who licence enzalutamide, say that it?s alright for men who have previously had abiraterone, to then have enzalutamide. Since the two drugs (abiraterone and enzalutamide) work very differently, there are potentially two different options that could help men with advance prostate cancer. But some men will only be allowed to access one of these options. This is very unjust, and like playing the lottery with lives - In the name of so called cost effectiveness.
Section 4 (Consideration of the evidence)	Time is of the essence for men who have advanced prostate cancer. And if they have previously had abiraterone, at the very least, they should be able to make an application to be given enzalutamide on a compassionate basis, until a more fair and positive decision is made about access to this drug. In addition; The Scottish Medicines Consortium has looked at the same evidence, and have approved enzalutamide without this restriction. Therefore I cannot understand why you will not allow men in this predicament to access a drug that could prolong their lives for a longer period.

Section 6 (Related NICE guidance)	Although cabazitaxel chemotherapy may be accessible to some extent, it is a brutal treatment that surely should be an absolute last resort for patients. Chemotherapy is a very toxic treatment, and providing men with an oral drug after they have already endured through grueling cycles of docetaxel, will provide a much better quality of life for them, and for their carers.

Role	Public
Other role	Consulting Engineer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The requirement not to have first been treated with abiraterone is arbitrary and not based on scientific evidence. Such a decision arguably amounts to malfeasance in public office. It takes no account of the eficacy of either drug in the treatment of an individual person. Scotland haas approved its use without conditions. You have a precedent set.

Role	other
Other role	Men United against Prostate Cancer
Location	Europe
Conflict	no
Notes	Wake up and provide the drug !!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should be available to all
Section 2 (The technology)	Drive down the price by giving it to more people. Economies of scale. Or buy it elsewhere
Section 3 (The manufacturer's submission)	no comment
Section 4 (Consideration of the evidence)	too much information
Section 5 (Implementation)	no comment

Role	Carer
Location	England
Conflict	no
Notes	The decision you have made to prevent men accessing enzalutamide, if they?ve previously had abiraterone is extremely unfair and heartbreakingly disappointing. Especially as this seems to be a very cruel u-turn on the part of NICE, since we were led to believe this was not going to be the case according to your original draft decision. Although cabazitaxel chemotherapy may be accessible to some

	extent, it is a brutal treatment that surely should be an absolute last resort for patients. From the research that I know about, it would seem that the company who licence enzalutamide, say that it?s alright for men who have previously had abiraterone, to then have enzalutamide. Also the two drugs work very differently, meaning there are potentially two different options that could help men with advance prostate cancer. But some men will only be allowed to access one of these options. This is very unjust, and like playing the lottery with lives - In the name of so called cost effectiveness. In addition; The Scottish Medicines Consortium has looked at the same evidence, and have approved enzalutamide without this restriction. Therefore I cannot understand why you will not allow men in this predicament to access a drug that could prolong their lives for a longer period. As I?m sure you can appreciate, with men who have advanced cancer, time is of the essence. And if they have previously had abiraterone, at the very least, they should able to make an application to be given enzalutamide on a compassionate basis, until a more fair and positive decision is made about access to this drug. My Dad has advanced prostate cancer and very sadly he is now running out of treatment options available to him. I am not ready to loose my Dad, and he is not ready to leave me. You have the power to potentially give us the chance to spend some more precious, precious time together. Ultimately this decision means life or death for my Dad. I am an only child and my Mum is also recovering from cancer. I am a carer for both of them. You have no idea how excruciatingly difficult it is to be in this situation. I?m desperately hoping that you will reconsider your decision, to give hope to my Dad, me, and other men and families who find themselves at this horrifically soul destroying crossroads.
Comments on individual sections of the ACD:	

Role	other
Other role	relative of patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1	It is neither fair nor scientifically justifiable to exclude patients

(Appraisal Committee's preliminary recommendations)	who have already had treatment with abiraterone for two reasons. Firstly, it is known that some patients cannot tolerate abiraterone, and they should not be excluded from trying the only other available treatment enzalutamide. Secondly, there is no clinical evidence one way or another whether patients already treated with abiraterone will respond to enzalutamide, since this group was explicitly excluded from participation in the enzalutamide clinical trials. It is not reasonable to exclude a group who may respond to treatment by enzalutamide just because this was one of the clinical trial exclusion criteria, any more than it would be reasonable to exclude potential patients meeting other of the exclusion criteria for the studies. There is quite literally no scientific basis for this recommendation, since there is no clinical data one way or the other as to efficacy. It is an untested assumption that the drug will not show benefit to this class of patients and they should be given the opportunity to try the drug.

Role	Public
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	- It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the o

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The proposal to not allow men who have been prescribed abiraterone enzalutamide seems to only limit futher thier options when the drug could provide them with further months or more with family and friends. The decision should match Scotland to allow enzalutamide after abiraterone if it if needed, so as to not restrict the routes to care that the men have available to them.

Role	other
Other role	[redacted]
Location	England
Conflict	no
Notes	I work for Prostate Cancer UK, but I am responding in a personal capacity. Prostate Cancer UK has not received any funding from Astellas, but has received gifts in kind from them up to the value of Â£2,000

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The fact that NICE is proposing to make enzalutamide available on the NHS is a good thing. However, I feel that the restrictions around previous use of abiraterone are unfair and should be removed ? on consideration of the same evidence, the SMC has approved enzalutamide post-chemo without restriction. I think that men suffering from advanced prostate cancer need as many treatment options as possible to prolong their life ? even the chance of a few more months is valuable. Finally, I don?t think that the reasons for a change to the initial draft decision (which had no mention of abiraterone) make sense, or have been sufficiently explained.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The patient is already at a crossroads of a seriously difficult time in his life. Why make him choose what treatments he can have? What if he hadn't realised he could only have one or the other, then what? It's unjust and unfair. There should be more options for men in these difficult situations, and your making the process even harder by adding in an extra difficult question half way down the line. Who are you, or any of us, to dictate if a patient can prolong their life? Surely, everyone deserves the right to treatment, and to prolong their lives?

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 9 (Sources of evidence considered by the Committee)	It is hard to understand any justification that men in the face of death would be denied a potential chance of extended life. I vehemently disagree with this. Those with life threatening illness should be allowed EVERY option at their disposal. We give more options and care to those who willingly harm themselves through obesity and alcoholism, yet we deny treatment to those who are blameless in their illness. It is a disgrace.

Role	Carer
Other role	ex teacher. Now Personal Assistant
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s great that Enzalutamide has been approved as an effective drug to treat men with advanced metastatic prostate cancer. It?s not good that the only other drug available to these men is Abiraterone. Men who have already received Abiraterone will

	have no other options available to them ? effectively pulling the rug from under them. This decision is unfair ? Clinicians can?t make an informed choice regarding which drug to give to which man, as both drugs work in a different way and we don?t know which will be most effective for which men ? Most affected men are older, depriving these men of Enzalutamide is discriminating against this section of society ? there is uncertainty surrounding aspects of the trial findings, eg, some men in the placebo group withdrew earlier from the trial, effectively ?skewing? the results ? withholding life extending drugs on this basis is unfair (especially when the Scottish Medicines Consortium have looked at the same evidence and have approved Enzalutamide without this restriction) ? This causes more stress for men at a difficult time ? Average life expectancy/reduction in pain ? many men live much longer than the ?average? as shown by Abiraterone

Role	Patient
Other role	Retired
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	All men with advanced metastatic prostate cancer have a right to have access to all life extending drugs ? what may seem just a small increase in life benefit to NICE in real terms is priceless and offers these men a ?breathing space? whilst other treatments are being developed. Many of these men are fit and well in themselves, despite the disease, and are leading a good life ? each drug on it?s own may not seem to have a great impact, but together they extend the lives of men, enabling them to spend precious time with their families. NICE?s decision is cruel ? to dangle a carrot, giving hope and then take it away is morally wrong. Which drug would a doctor prescribe? Not enough is known about which drug works best for which men At a time when these men are already suffering, it is wrong that they should have to make further difficult decisions The Scottish Medicines Consortium have looked at the same evidence and have approved Enzalutamide without this restriction Restricting Enzalutamide will adversely affect men?s willingness to take part in often arduous trials, thereby affecting future research potential for a disease which has been historically underfunded

Role	Carer
Other role	ex teacher. Now Personal Assistant
Location	England
Conflict	no

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s great that Enzalutamide has been approved as an effective drug to treat men with advanced metastatic prostate cancer. It?s not good that the only other drug available to these men is Abiraterone. Men who have already received Abiraterone will have no other options available to them ? effectively pulling the rug from under them. This decision is unfair ? Clinicians can?t make an informed choice regarding which drug to give to which man, as both drugs work in a different way and we don?t know which will be most effective for which men ? Most affected men are older, depriving these men of Enzalutamide is discriminating against this section of society ? there is uncertainty surrounding aspects of the trial findings, eg, some men in the placebo group withdrew earlier from the trial, effectively ?skewing? the results ? withholding life extending drugs on this basis is unfair (especially when the Scottish Medicines Consortium have looked at the same evidence and have approved Enzalutamide without this restriction) ? This causes more stress for men at a difficult time ? Average life expectancy/reduction in pain ? many men live much longer than the ?average? as shown by Abiraterone

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	"Enzalutamide is recommended as an option for treating hormone‑relapsed metastatic prostate cancer in adults, only if: ?their disease has progressed during or after docetaxel-containing chemotherapy and they have not had treatment with abiraterone". This is so unfair to those of us who have been told that we need treatment. Why deny our group treatment that can prolong our lives when millioins in other cancer groups and with other condiotons have MILLIONS spent on them?

Role	Public
Other role	
Location	England
Conflict	no
Notes	I object strongly to the unfair and invidious decision regarding the prescribing of enzalutamide
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is very unfair and invidious to both patients and doctors/consultants. There should be no "either/or"

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Whilst welcoming the approval of EnzalutamideI am concerned that its use will be restricted to patients who are not being treated or have not previously been treated with Abiraterone. I think this is a mistake and will place patients and practitioners in an extremely difficult position having to make a decision between the two drugs at a very stressful moment in the treatment programme. They will be in the innocuous position of having to take this decision without any clear evidence basis of which of the two drugs is likely to be most effective for that specific patient. I am currently undergoing treatment for locally advanced prostate cancer with Zoladex following external beam radiotherapy at the end of 2013. I have a further concern that at the beginning of my treatment last summer I was offered the opportunity of taking part in the STAMPEDE trial which involved trialling Abiraterone in the early stages of treatment. In the end I decided not to take part in the STAMPEDE trial, but I am concerned how this proposed rule would affect those who have taken part and already been treated with Abiraterone.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	By adding the rider that abiraterone users will not be considered for enzalutamide are condemning those who did not have a choice. This must be a limited group that will only get smaller. Why not a discretionary decision on using enzalutamide.

Role	Public
Location	England
Conflict	no
Notes	Nice !.. Not the choice of word to describe these actions, we spend millions on foreign aid and I do not think it is unreasonable for a bit of attention to us Men that seem to be being pushed in the corner to die at a time when we should have a helping hand. RE THINK ... Use common sense not a senseless act that can be reversed. Please . [redacted]

Role	Public
Other role	Retired
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	All treatments and drugs available should be used in the fight against cancer, therefore this whole recommendation should be deleted
Section 2 (The technology)	2.3 should be deleted. While there are funds available for foreign aid,no amount should be to much to fight prostate cancer in this country
Section 3 (The manufacturer's submission)	Any information regarding cost should be removed. Whether a drug is used should be decided on the benefits it can give not the cost of providing it.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that this treatment should be available to all patients under medical supervision.
Section 2 (The technology)	I believe that the cists will significantly reduce with mass ordering available to the NHS.
Section 3 (The manufacturer's submission)	I believe that cist should not be the primary driver in deciding therapy for any disease and that this drug should be made available to all patients regardless of previous therapy/treatments employed.
Section 4 (Consideration of the evidence)	The statistical analyses presented by both sides are understandably skewed by the presenting organisation in favour of that organisation. The truth is that more men would survive for I nger ufvthus treatment is made available it the oncologists discretion.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	should be available to all men
Section 2 (The technology)	should be availble whatever the cost-the government should control this in some way
Section 3 (The manufacturer's submission)	too much information for a normal person, just provide the drugs!
Section 4 (Consideration of the evidence)	medical practioners are the people to decide if a patient needs this not the cost of the drug
Section 5 (Implementation)	no comment
Section 6 (Related NICE guidance)	no comment
Section 7 (Proposed date of review of guidance)	no comment
Section 8	no comment

(Appraisal Committee members)	
Section 9 (Sources of evidence considered by the Committee)	far far too much information for a normal person!

Role	Public
Other role	Daughter of patient
Location	England
Conflict	no
Notes	In the last 18mths both my father and father in law have been diagnosed I just want my Daughter to know her grandparents this pill should be available to all men.

Role	other
Other role	Daughter of a prostate cancer patient
Location	England
Comments on individual sections of the ACD:	
Section 2 (The technology)	Prescribe it if needed, not if cheap.
Section 3 (The manufacturer's submission)	Prescribe it if needed, not if cheap.
Section 4 (Consideration of the evidence)	Prescribe it if needed.
Section 5 (Implementation)	Prescribe it, not be cheapskates

Role	Public
Location	England
Conflict	no
Notes	I would like the drug enzalutamide to be made available to all of the United Kingdom . I fought for this country in Northern Ireland back in 1971/2 to help those with different views to live where they wanted and to keep the Uk united. Now your saying a life extending drug is not available in the UK except for those living in Scotland. I think you are abusing the rest of the UK by withholding such treatment. I also think more funding should be made available for research into prostrate cancer. Just because men don't shout out the problem why is breast cancer any more important. Its time this country got their act together and started helping the older generation who are the grass roots of the country, instead of giving away billions of pounds in foreign aid. Where is the rest of the world when disasters hit our country,LOOKING after their OWN.

	Take the floods that are happenning now! Where and what help are the sufferers getting. We should do more of the same and put the GREAT back into Britain. I am nearly ashamed of calling myself English. Perhaps we should all wear bandages wrapped round our heads ,then we would get better service from those in charge. Buck up!!!!!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 2 (The technology)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 3 (The manufacturer's submission)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 5 (Implementation)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 6 (Related NICE guidance)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 7 (Proposed date of review of guidance)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.
Section 8 (Appraisal Committee members)	Would you get hold of any drug by payment if that drug was to extend your life?
Section 9 (Sources of evidence considered by the Committee)	If any drug can extend a persons life ,it should be made available to them. Do not discriminate by just allowing a portion of the UK to have it.Keep the UK united.

Role	Patient
Other role	Journalist
Location	England
Conflict	no
Notes	I survived prostate cancer after being treated 5 years ago and firmly believe that ALL men over the age of 50 (at the very least) should be given the opportunity for an annual test for prostate cancer, similar to breast screening for women. Also, all men whose family members have had prostate cancer should be regularly checked, possibly from a much earlier age. This, in my opinion, would save lives for as you know, the earlier the better chance for survival.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	ANY treatment that helps men survive prostate cancer must be a good investment for it has a huge potential for saving lives (and, in the long term), money.
Section 2 (The technology)	I think this treatment should be available. Presumably, the more patients who are prescribed should in the long run bring down

	costs. If not, why not?
Section 3 (The manufacturer's submission)	I think the costs seem somewhat prohibitive but again, as already mentioned, I would hoep that the more men who are treated will a) reduce other costs for dealing with this pernicious illness and b) help drive down those costs. But then I am of the opinion that pharmaceutical companies are in the business of making money and need to be encouraged to not only create and produce treatments such as this, but look at reducing costs to the consumer and NHS. For only then will men in other poorer countries be able to get this kind of treatment.
Section 4 (Consideration of the evidence)	Bottom line: what is the life of a man with prostate cancer worth. In my opinion, every penny spent. The same applies to other necessarry treatments. Nevertheless, one of the most vital considerations is for pharmacetical companies to take a much more searching look at their overheads, and drive them down to levels that are acceptable and manageable by NHS and similar bodies, who are all facing cuts in services. If pharmaceutical companies don't look at this and deal with it, all they'll be doing is ruining their own financial future. It's in everybody's interest to make sure vital and necessary treatments are available and affordable.
Section 5 (Implementation)	Just get on with it, asap. Men are dying.
Section 9 (Sources of evidence considered by the Committee)	I'[ve read, think you should go ahead. Don't let me stop you. Men are dying and families are suffering.

Role	Public
Location	England
Conflict	no
Notes	Previous cancer sufferer, now in full remission (Lymphoma)
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This should be available to all sudferers, otherwise you can not ever come to a proper conclusion on if, or why it may or may not work. How would we ever know if it could suddenly become a life saving factor in those that are not allowed the drug. This is just so short sited, especially as it looks as though the decision has been taken on the cost basis, where that should never be a factor. I wonder if those that decide, especially the male, or females, malke partners were ever to be infected, how would that be dealt with? On the same basis as the rest of the general public? I very much doubt it, and hopefully no poor soul ever gets it, but, everyone deserves the second chance of life.
Section 2 (The technology)	I think this is a fair price to pay for someone s life, especially when we spend more on arms and weapons of destruction, this is a mere pittance in comparison. How can you value a life so cheaply?
Section 4 (Consideration of the evidence)	Some of the evidence at best arbitrary, and at worst contradictory. Although the general direction of these statements head in the same direction, a few dont, and that alone would convince me that even more trial evidential work

	should be undertaken, with a very large sample. You as a body are in the position to be able to do this, and it would hopefully aid the decision once and for all.
Section 5 (Implementation)	Are the costs the same for each NHS authority, or is this again by post code. If its being undertaken in secret, then it implies that you have things you need to hide from public gaze? Why?
Section 6 (Related NICE guidance)	If the regimes for treatment are in fact now outdated, as in some cases (2008) Maybe a better course of action and implementation with a set of later modern drug treatments. People dont have lots of time if there unwell, so any chance of a better course that those currently being offerd should be the first priority.
Section 7 (Proposed date of review of guidance)	This is far too late, and it should be undertaken on a 90 day review. How can you just push for a two year cycle, its not ethical, or even warranted.
Section 8 (Appraisal Committee members)	Too many experts on these committees, maybe some more people that actually have the disease, so a valid opinion could be taken from them and then added to the general evidence for each team, and as a general information for all memebers. Too mayn closed doors I suspect in the team structures, these should be more open and divesrse in the way the knowledge/decisions/information is studied and acted upon.
Section 9 (Sources of evidence considered by the Committee)	There should be more Patient experts that could be called upon, and their particular information should be made available to all participants. The list of those chosen to participate looks very good though.

Role	Patient
Other role	Member of High Peak Prostate Cancer Support Group and active in PCSFederation
Location	England
Conflict	no
Notes	After 1 Docetaxel regimen, I took Abiraterone (AA) from June last year, with immediate 52% PSA reduction, until November when it ceased to control my PSA. Enzalutamide (E) is now one of the very few options left to me. I had no reason to decline AA in June,in line with NICE guidance for post-Docetaxel treatment. Professionals and charities predicted last year that post-Docetaxel E would be approved this month (February). For others as well as me, the decision to exclude it in this second consultation document is thus a cruel, life limiting, reversal of future option assumed when agreeing to AA.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	[1.1] Exclusion of prior Abiraterone (AA)treatment is unreasonable in the light of patient evidence and duty of equitable care. This view is shared by similar patients and by professionals who will no doubt also comment here. Further comments below support my appeal for its removal. There has been widespread expectation, including consultant opinion to patients, that Enzalutamide (E) would be available to those whose post-Docetaxel AA treatment failed, and consequently a

	sense of dismay and betrayal of hopes.
Section 2 (The technology)	[2] As quoted here existing marketing authorisation does not state an exclusion of AA taken between Docetaxel and E. Patients reasonably interpret this as allowing it.
Section 3 (The manufacturer's submission)	[3.8]Not stated here is relative PSA Response in COU-AA-301 (29%) and AFFIRM (54%), a significant advantage of E.
Section 4 (Consideration of the evidence)	[4.0] I strongly endorse the importance of patients' value judgement, and [4.1] value of all improvements in Quality of Life, and of hope. [4.20] The restriction applies to a reducing no., meriting a special case. [4.18] New evidence led the Committee to add availability for >1-Docetaxel patients to its recommendations using End-of-Life criteria. Similar action is justified for post-AA use on evidence of patient experience and from Schrader et al.(Euro Urol June 2013/Feb 2014), not included above [4.22 and Summary]. 54% had clinical benefit. PSA Response of appx 29% was the same as that in COU-AA-301, which justified NICE approval of AA post-D. There is adequate justification for approving E post-AA, for the small no. affected pending further evidence of experience.
Section 5 (Implementation)	[5] I appeal for availability to the limited group of Docetaxel+AA patients ruled out by the Committee's restrictive recommendation. I suggest this be CDF-funded on consultants' recommendation and patients' informed consent.
Section 9 (Sources of evidence considered by the Committee)	[9] As noted above the evidence did not include the study by Schrader et al. which though on a limited sample indicates benefit to a significant proportion of patients from E+AA. Just as scope was extended post-ERG to >1 Docetaxel regimens on manufacturers' evidence apparently without full formal trial, I urge that their evidence from post-AA patients supplied with E free-of-charge, and Schrader's evidence, be taken into account.

Role	other
Other role	Man with prostate cancer and volunteer with Prostate Cancer UK
Location	England
Conflict	no
Notes	I am a retired solicitor and law lecturer with prostate cancer and have been a volunteer with Prostate Cancer UK since 2008. My roles there include membership, as a lay person, of its Research Advisory Committee, its Grants Advisory Panel and its Education Advisory Group.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The approval of Enzalutamide, as an effective drug for Advanced Prostate Cancer, is to be commended. However, the restrictions on its use are illogical and not in the best interest of the patient. The following are reasons why I consider this to be the case: ? If Enzalutamide is shown to be effective, without men receiving first receiving Docetaxel treatment, it would be unfair

	for them to have to take Docetaxel first, as Docetaxel may be ineffective and/or cause the patient serious side effects. ? Men will have to decide, at a very difficult time in their lives, whether to follow an Enzalutamide or Abiraterone course of treatment, without knowing which will be the more effective and/or which will have the less serious side effects. They will, in effect, be taking a gamble on which drug to take, the results of which may have life threatening and/or serious personal welfare implications. ? The restrictions raise difficult ethical and legal issues for consultants advising on which drug treatment to recommend, as he/she is bound to act in the best interests of the patient and will have little, if any, information as to which treatment will best suit the patient.

Role	Patient
Other role	Prostate cancer survivor
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The requirement to NOT have been treated with abiraterone first is illogical. the decisions men have to make during treatment are already very stressful and this will add another one at a very difficult time in men's treatment.

Role	Public
Location	England
Conflict	no
Notes	Few colleges have had prostate cancer and its really damaged their lives. If there has been improvements made people should have access to them.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As long as its available at the right time, and not when its too late.
Section 2 (The technology)	Shame it costs so much, R&D is adding to the cost of this but its understandable.
Section 3 (The manufacturer's submission)	too long didn't read.
Section 5 (Implementation)	"Give me Drugs, Now!"
Section 6 (Related NICE guidance)	Lots of good info available.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1	Any medical option should be available to sufferers

(Appraisal Committee's preliminary recommendations)	irrespective...!!!
Section 2 (The technology)	Cost shouldn't be a discussion point - start controling the drug comapnies, not the lives of sufferers..!!!
Section 3 (The manufacturer's submission)	Any extension to life no matter how small is of benefit to a sufferer.
Section 4 (Consideration of the evidence)	Quit playing gods accountant - if the treatments works, no matter how small a difference, the patient should decide..!!
Section 5 (Implementation)	Cost, cost, cost, cost, cost...!!!!
Section 6 (Related NICE guidance)	Listen to the patients and their families...!!

Role	Public
Location	England
Conflict	no
Notes	If there is any meds which can aid or improve the life of someone with Prostate Cancer, then they should be available no matter what. Are we putting a price on human life?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If this is available it should be given to all who need it.
Section 2 (The technology)	We need to look at if this is able to be given earlier if it stops growth of cancer, while still monitoring its effects.
Section 3 (The manufacturer's submission)	Trials should not be run by the manufactuers of any drug, it should be tested by an independant group so as no results can said to be compromised. Price should never be an issue when it comes to cancer drugs. More research needs doing into this as it would seem not enough has been cecked properly.
Section 4 (Consideration of the evidence)	It would seem to me that this document is very repetative and seems to try and direct you away from making the right decision with all its waffle. If this drug is available and is best for use, use it no matter what. We all deserve the best treatment, I myself have several illnesses and if it wasn't for the NHS I would not be able to get what I need free. If I had to pay I would have to choose either my bills or my meds.
Section 5 (Implementation)	NICE need to stop dragging there arses in the mud like they always do.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I wish to support the Prostate Cancer UK response that welcomes the approval of enzalutamide, but that raises concern that the restriction has been applied. This is bad news for men who have tried abiraterone already and have limited treatment options available to them. As abiraterone and enzalutamide

	work differently it will be difficult for clinicians to decide what drug to administer if they do not know which one will work best for which patients. The Scottish Medicines Consortium have used the same evidence that NICE have used but have approved the drug without restrictions. My Father has advanced cancer and any possible treatment solution offers a glimmer of hope. There are not many options anyway and this decision will remove one of few options available. Please reconsider.

Role	Public
Location	England
Conflict	no
Notes	Diagnosed with Prostate Cancer though no treatment given other than 'watch and wait' with 2 yearly biopsies.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This stipulation greatly reduces choices at a time when it simply is not clear which drugdrug treatment is the most appropriate. Scotland has different rules too.
Section 2 (The technology)	There appears to be different emphasis on costs regarding men's health issues and female issues and also what is thought appropriate in Scotland.

Role	Public
Location	England
Conflict	no
Notes	This drug should be made available to all patients across the UK
Comments on individual sections of the ACD:	
Section 9 (Sources of evidence considered by the Committee)	We need this drug available to all in the UK not just the Scottish. I presume it is the British tax payer who pays for this. What happens if the Scottish vote is yes. How will this drug then be funded?

Role	Patient
Other role	[redacted] Friends of Prostate Sufferers
Location	England
Conflict	no
Notes	See for background www.thefops.org.uk
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Dear Sir/Madam. The Friends of Prostate Sufferers (FOPS) have just heard that NICE will no longer be prescribing Enzalutamide after Abiraterone has failed to keep PSA low in patients with metastastic prostate

	cancer.. CAN THIS BE TRUE?. Recent trials have proven that using Enzalutamide on men with metastatic prostate cancer gives on average SEVENTEEN MONTHS of extra life before the end game starts with Chemo being prescribed. So NICE's recent arbitrary decision to remove access to Enzulatamide, the life enhancer if you had Abiraterone before Chemo, is removing life from considerable numbers of men whose lives would on average be extended by 17 months by using Enzalutamide. All of North America is using it, nearer home Scotland is using it..Why are you condemning poor English and Welsh souls to early deaths? PRESS RELEASE Jan 28th 2014 "Medivation and Astellas Announce Final Results from the Phase 3 PREVAIL Trial of Enzalutamide in Men With Metastatic Prostate Cancer Progressing on Androgen Deprivation Therapy. Study Demonstrates Statistically Significant Benefits in Overall Survival, Radiographic Progression-Free Survival, and a Delay (17 Months) in the Time to Initiation of Chemotherapy. So, why is your organisation NICE denying this extended life opportunity to British patients. Please revert to prescribing Enzulatamide when the Oncologist deems it necessary, as is still the case across the Scottish Border. Its efficacy could/should, of course, be monitored by monthly PSA testing."

	Copywright mainly but not exclusively [redacted]

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Proposal to make the drug available and the removal of the qualifications re number of docetaxel treatments are both welcomed.The guidance is clear in effectively pointing to use of enzalutimide as the first choice treatment post chemo failure where appropriate.Physicians and patients would then still be able to consider and have abiraterone as a later option. There are though a group of patients who have now already had abiraterone,some will also have derived no benefit & then gone on to cabazitazel or docetaxel rechallenge etc. it seems very unfair that the guidance as drafted then denies this group access to enzalutamide which may now be their only treatment option.Earlier draft guidance also omitted any consideration/mention of this raising hopes. I would urge NICE to address this anomaly and unfairness.If implementation the clauses preventing access to enzalutimide after abiraterone use were to be deferred for a period after the guidance was finalised all existing patients & their physicians would retain treatment options.

Role	Patient
Location	N Ireland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is good news that enzalutamide has been approved for use as trials show that it significantly extends life compared to a placebo. However, the decision not to allow men who have received abiraterone to be given enzalutamide is outrageous and an unwarranted restriction of clinical judgement. No convincing explanation for this decision has been given. What NICE has done is to pass enzalutamide for use, but make it totally unusable. Nearly everyone who needs enzautamide at the moment has been given abiraterone and unless the restriction is taken out, they are all going to die. Abiraterone has ceased to be effective for me (my PSA has rocketed) and my oncologist would administer enzalutamide if allowed to. Instead I will only receive it if I ?self finance? i.e. pay Â£2,700 per month from my own pocket to buy the drug privately: I am a pensioner ? where will I find that kind of

	money? The European Association of Urology has concluded that ? a significant number of patients can benefit from sequential treatment with abiraterone followed by enzalutamide?. This is in line with the Scottish Medicines Consortium who have approved enzalutamide without this restriction.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why is there a recommendation not to treat those who have previously been treated with abiraterone? The argument surely cannot be that those previously treated with abiraterone were excluded from the enzalutamide trial (and thus there is no evidence that these men will benefit from treatment). Many different sorts of patients (including a number of groups who were never treated with aberaterone) were excluded for the purposes of the enzalutamide trial. Why single out those patients who have been treated with aberaterone and have either relapsed, or simply failed to tolerate it (I know of both types of patient). Despite targeting a similar pathway, it is unclear whether either abiraterone intolerance or resistance means enzalutamide intolerance or resistance. In terms of cost I would have thought that a consultant can make a judgement about whether a patient tolerates and responds to enzalutamide and can withdraw the drug if there is no positive outcome.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It would appear that the NICE decision is due to lack of evidence on the interaction between this drug and abiraterone. But as this is an late treatment option if the drug has undesired side effects,or is of limited effectiveness - then this will quickly become apparent through case studies.
Section 2 (The technology)	Presumably a very large commercial discount can be negotiated.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment

	options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Carer
Other role	Wife
Location	England
Conflict	no
Notes	I strongly object to the withdrawal of enzalutamide making it unavailable to my husband. He was put on a trial treatment offered to him by his consultant without being given a choice. Aberaterone has been given for the past 16months to treat his advanced prostate cancer. It appears to be holding the disease but should the need arise how can you justify withholding further life saving treatment? Scientists have worked long hours to develop these treatments and if they are not available to men who have had aberaterone how can they ever be assessed as successful?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is an unfair decision as it discriminates against men who have been treated with Abiraterone. In my husband's case it was given without him being given a choice.

Role	Public
Location	England
Conflict	no
Notes	My Doctor currently has me on Finasteride tablet one per day.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Enzalutamide should be available regardless just as it is in Scotland
Section 2 (The technology)	Points noted.

Role	Public
Location	England
Conflict	no
Notes	Please do the right thing!

Role	Public

Other role	None
Location	England
Notes	It is good that enzalutamide has been approved - it's an effective drug and we want it to be available to men with advanced prostate cancer. This situation is bad news for men who already have limited treatment options - abiraterone is the only other drug available to them. This complicates the situation for men at an already difficult time. This marks the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can't tell in advance which will work better for which men. The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Unfair and inherently gender discrimination. Disagree should be available for use without conditions.
Section 2 (The technology)	No comment
Section 3 (The manufacturer's submission)	No comment
Section 4 (Consideration of the evidence)	No Comment
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No Comment
Section 8 (Appraisal Committee members)	No Comment
Section 9 (Sources of evidence considered by the Committee)	No Comment

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1. The restriction that enzalutamide should be recommended only if: ?their disease has progressed during or after docetaxel-containing chemotherapy and they have not had

	treatment with abiraterone? is unjustified, particularly in view of the evidence of the recent PREVAIL trial. The committee should therefore remove this restriction pending detailed consideration of the new evidence.
Section 2 (The technology)	2. Interestingly, there were no seizures in the larger PREVAIL trial among patients who did not have a prior history of seizures.
Section 3 (The manufacturer's submission)	3. The manufacturer should be invited to present the findings of the latest trials at the earliest opportunity.
Section 4 (Consideration of the evidence)	4. In the light of the publication of the PREVAIL trial, the committee must now reconsider the recommendations of para 4.8, which even as they stand, suggest that any chemotherapy might reduce the effectiveness of the drug. The argument underlying para 4.22 is unclear or flawed. If there is "no evidence", it ought not to be possible to draw a conclusion, let alone the one that has been drawn. The key conclusion that the drug should only be administered post chemo and not to patients who have previously had abiraterone does not reasonably follow. Indeed, current evidence is that Enzalutamide is a potential first-line treatment for CRMPC. To recommend administration of a proven effective drug in only the final stages of a disease, for no good reason, or none that has been presented, gives rise to the suspicion that the motivation is cost-driven. If the QALY calculations are redone for pre chemo expectations, it is likely that cost effectiveness will be found to be improved (though not the overall cost, unless and until further discounts can be obtained and/or the price falls.)
Section 5 (Implementation)	5. Para 5.2 Remove "in line with NICE?s recommendations". These should not override the doctor when the doctor knows more about the disease and the patient.
Section 6 (Related NICE guidance)	no comment
Section 7 (Proposed date of review of guidance)	7. This would be an inappropriately long wait to consider important new evidence that is available now. The committee urgently needs to review its findings immediately.
Section 8 (Appraisal Committee members)	8. The committee is being blinded by statistics. Trials may show that a treatment is effective in a population, but not that it is effective for all patients in that population. PC is a highly variable disease and much more needs to be learnt about it. Unless clinicians are given some discretion to administer treatments according to their advancing knowledge of how the treatments work and their assessments of patients' needs and thereby gather experience of how to refine those treatments, we will not make progress, and medicine will return to a blind methodology reminiscent of medieval times. This is poor outcome for patients. The committee, in my opinion, should be careful not to limit clinical options without good reason. Where decisions of the committee have a clinical impact, as they do here, those decisions should be scrutinised by senior clinicians who are recognised experts in the disease. Such expertise is much too poorly represented on this committee.
Section 9 (Sources of evidence	9. The committee has failed to consider all of the evidence available at the time of consultation.

considered by the Committee)	

Role	other
Other role	Wife
Location	England
Conflict	no
Notes	My husband has advanced metatstatic prostate cancer. The options open to him are limited and Enzalutamide should be the treatment of first choice for patients like him who might then go on to Chemotherapy if this treatment fails. It is a cynical ploy to make patients undergo Chemotherapy before newer treatements are permitted under the NHS. Invariably the decimation that occurs with chemo reduces the cost to the NHS of these newer drugs because the patient dies before they can be prescribed, or if they are lucky to survive the rigours of chemotherapy, they have very few months left to be a burden on the Health Service. My husband is still working and paying taxes. Why should he be denied these newer treatments when he has years of useful life left. The NHS should stop funding vanity projects like IVF and concentrate on life-threatening diseases like Prostate Cancer which cause so much devasatation to families. It is not just old men who suffer from it and NICE should remember this in their deliberations. Breast Cancer Patients don't have the same unfair treatment so why should Advanced Prostate Cancer Patients?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Enzalutamide should be the treatment of first choice not second. Denying patients this novel treatment and restricting it to those who are abiraterone naÃ¯ve is unfair.
Section 2 (The technology)	Docetaxel is over 10 years old and it should not be given as much precedence as it is currently. Newer medications need to be employed with patients from which useful data can be procured as to its effectiveness in the clinical rather than trial environment.
Section 3 (The manufacturer's submission)	I am not qualified to comment on the technical aspects of one drug -v- another. What I am qualified to do is comment on the amount of taxation that an individual paying higher rate tax will contribute to the economy and the NHS if they wer e permitted a longer lifespan with drugs such as Enzulutamide. The product has been licensed in the USA and Europe, so why does NICE feel it can dictate to patients that they are not worthy of the newer treatments coming to market.
Section 4 (Consideration of the evidence)	Three months extra life to someone without cancer might seem like nothing and not worth the price of the medication. If the cost per life year is correct and patients only get three months, there is a flaw in the calculation. If someone is paying tax of Â£12000 per annum then the cost of the treatment is less because the patient can continue working and can provide for his family.
Section 5 (Implementation)	NICE seem to make things unnecessarily complicated. Hospitals receive money to treat patients; this should include all

	drugs necessary. Swings and Roundabouts.
Section 6 (Related NICE guidance)	The Drug Company producing Abiraterone will obviously be concerned that there is potential for their market share to be reduced and no doubt will be lobbying hard for the newer drugs to be "rationed" until they have received sufficient remuneration to cover their drug development costs.
Section 7 (Proposed date of review of guidance)	This date is not soon enough for people who are running out of time. Three months is all that some people have left when they have Prostate Cancer and NICE should not be ignoring this imperative, which is to the detriment of so many patients and their families.
Section 8 (Appraisal Committee members)	NICE should consider inviting one of the leading specialists in Prostate Cancer to sit on its panel.
Section 9 (Sources of evidence considered by the Committee)	Evidence should have been sought from patient suffering the disease as to their thoughts on their treatment options. It might have helped the Committee formulate a more helpful stance.

Role	Public
Location	England
Conflict	no
Notes	Lets level the playingfield, Men are traditionally bad at looking after their health. The continuing focus on mens health will have overall societal impacts, especially when men, impacted by health concerns, have wider impacts on their families, friends and relations. Prevention is better than cure.
Comments on individual sections of the ACD:	

Role	Patient
Location	England
Conflict	no
Notes	After diagnosis I was asked if I would like to participate in a clinical trial. I agreed, having the stipulation that I would accept one of five options. Abiraterone was one of them and that was chosen "by the computer". Enzalutamide was not an option. I consider it unfair that I am now prevented from having this second treatment, should my consultant think it of benefit, when others may do so.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have metastatic prostate cancer. It is being treated by Abiraterone. If clinically advised I should have access to this drug if others do as I have not had an option to choose before.

Role	Patient
Location	US
Conflict	no
Notes	I'm currently taking Zytiga and believe that in the event Zytiga fails that Xtandi should be available. There is no evidence that Xtandi does not work after Zytiga has failed. Men with

	advanced prostate cancer should not have a proven medications withheld from them for what seems to be economic reasons. NICE?s decision to withhold Xtandi after Zytiga failure is not evidence based. If the lack of studies is to be considered evidence then on the same logic NICE should not permit men to have Jevtana (cabazitaxel) after Zytiga or chemotherapy after Zytiga because there is no evidence that this protocol is effective.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Illogical and unfair decision to restrict the use of the new drug Enzalutamide for men who have been treated with Abiraterone.

Role	Public
Location	England
Conflict	no
Notes	all forms of medication should be available to everyone in the UK
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	all medication should be abvailable
Section 2 (The technology)	price should not be an issue

Role	other
Other role	Close relative of a patient and campaigner
Location	England
Conflict	no
Notes	An inequality between England and Scotland. All patients should have opportunity and right to access cancer drugs on the NHS regardless of where they live. Patients and their families raise funds and dedicate their time to support research/trials in the hope new treatments will become available, it's unjust when a new treatment does become available patients are being denied them, dashing hope of prolonging life. Life prolonging drugs should be available to all patients without them having a challenge or in many cases putting themselves into financial difficulty trying to fund the much needed drugs.

Role	Public
Location	England

Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	doscount.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	the treatment should be available in any case where it is recommended by the patient`s consultant. The amount of money spent on combatting the most common cancer in men is a fraction of that spent on combatting breast cancer in women

Role	Patient
Location	England
Conflict	no
Notes	Given the underfunding of research All treatments should be tried, especially in combination to discover effective remedies. As my doctor put it on receiving my PSA test after hormone and radio therapy 'your cancer appears to have gone to sleep'. It is not cured and the two consultants who have looked after me differ on whether I should have three more years of hormone treatment or not. I would like to know that I am getting the best treatment not the cheapest.

Role	Patient
Location	England
Conflict	no
Notes	I believe that NICE are wrong in the decision they have have made as it has be clinically proved that the medication works and can both improve and lead to a longer life. Cost should not be looked at when it comes to a persons life.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that Enzalutamide should be given when a consultant thinks it could help.
Section 2 (The technology)	cost should not be inhibitor to treatment
Section 3 (The manufacturer's submission)	Tests confirm the drug works and should be added to NHS list of treatments.
Section 5 (Implementation)	It has to be recommended as a frontline treatment

Role	Patient
Location	Scotland

Conflict	no
Section 4 (Consideration of the evidence)	I am not clear if you have considered whether the early use of enzalutamide would increase the rate of survival over the use of other options. If you only recommend it in the end-of-life phase, you seem to be wasting its potential to win improvements in health earlier on in the disease phase. I currently live in Scotland, but move between England and Scotland as work determines. It strikes me as being almost immoral that I would qualify for this treatment on one side of the border and not the other.

Role	Public
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s good that enzalutamide has been approved, it looks like it will be an effective drug and we want it to be available to men with advanced prostate cancer. This restriction is bad news for men who already have limited treatment options, abiraterone is the only other drug available to them. Why should my Dad that lives in England be denied the opportunity to receive this drug, where if he moved to my flat in Scotland he would have a the full range of treatments that have already been approved by the Scottish Medicines Consortium. This is a group that have looked at the same evidence and have approved enzalutamide without this restriction.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This reduces the options for care and has no scientific basis.

Role	Patient
Location	Scotland
Conflict	no
Notes	My thoughts on this rather discriminatory decision are that if this were a "female breast cancer" decision there would be a public outcry. We, as men have every right to expect and demand the best possible care when undergoing treatment for this disease. I am lucky in as much I was diagnosed early and received exemplary care and treatment, brachytherapy, at the Western General Hospital, Edinburgh. This does not ensure my condition will not return and I would as a Scottish resident receive the correct treatment to ensure I had as long and comfortable life as possible. It is not right that this does not

	extend to the rest of the UK.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Yet again we are treating life as if it had a monetary value. Discount! what a nonsense. Also why if one treatment fails should another one not be available. Nonsense!
Section 2 (The technology)	Why the secrecy over the discount available? This is our NHS and under freedom of information it should be available. If Doctors decide this is the best treatment it should be available.

Role	Public
Location	England
Conflict	no
Notes	I want the same opportunities for medical help, with regard Prostate cancer, as men in Scotland. Government promised me the best proper and relevant medical help from cradle to grave. I expect nothing less.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I want the same opportunities for medical help that men is Scotland get. Government promised me the best medical treatment from cradle to grave. I expect nothing less. No exceptions. No moving the goal posts.
Section 2 (The technology)	If it works as a treatment I want it to be available to me sooner rather than later.
Section 3 (The manufacturer's submission)	If the medication works it should be made available without a price tag.
Section 4 (Consideration of the evidence)	I have paid into the NHS all my life I expect to be given the very best treatment for whatever I am suffering from with out limiting my medication on the grounds of cost.
Section 5 (Implementation)	If treatment costs more then take more in taxes to cover the cost.. Politicians should not put their re election before the public health.
Section 6 (Related NICE guidance)	This sort of paper reading matter is not user friendly. You are there to do your best for the general public. Do your job.
Section 7 (Proposed date of review of guidance)	It can't happen quick enough. get on with it, A S A p.
Section 8 (Appraisal Committee members)	High powered list of names. Are there any conflicts of interest?
Section 9 (Sources of evidence considered by the Committee)	How much time have these people put into researching the evidence or was it just rubber stamped?

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Propose that strong negotiation tales place to ensure maximum discounts to the NHS.

Section 2 (The technology)	If Scotland can pay this then the rest of the UK MUST follow suit, see earlier comments re discounts.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should be available to all, no one should ever be judged.
Section 2 (The technology)	Wrong to have to pay for your life, guess it's ok for the upper classes
Section 4 (Consideration of the evidence)	Seems people are judged on there status in life not equality
Section 5 (Implementation)	The goverment should enforce a law to implement the use to all patients
Section 9 (Sources of evidence considered by the Committee)	Should not need recommendations on saving peoples lives

Role	Public
Location	England
Conflict	no
Notes	We all live in the UK and pay our taxes to the UK, hence we should have the same rights and access to medication as Scotland. Patients of England, Wales and N. Ireland should have their choice restricted. More testing and data is required before such cost savings are introduced.

Role	Public
Location	Wales
Conflict	no
Section 4 (Consideration of the evidence)	The decision to restrict the availability of this treatment to advanced suffers who have already had the variety of treatments mentioned above seems arbitrary. I would draw your attention to the lack of publicity regarding this variety of cancer compared to others, as well as a lack of investment into the treatment of it. This in my opinion makes your decision questionable - due to these factors there are little options for suffers of this disease already, without your additional restrictions.

Role	Public
Location	England
Conflict	no
Notes	I am opposed to restrictions on potentially lifesaving drugs for treating prostate cancer

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Reasonable
Section 2 (The technology)	Not always applicable?
Section 3 (The manufacturer's submission)	Far too technical
Section 4 (Consideration of the evidence)	Expensive and not cost effective in all cases
Section 5 (Implementation)	Fair enough
Section 6 (Related NICE guidance)	Noted
Section 7 (Proposed date of review of guidance)	Fair enough
Section 8 (Appraisal Committee members)	Appropriate
Section 9 (Sources of evidence considered by the Committee)	Also appropriate

Role	Public
Location	England
Conflict	no
Notes	It's good to hear that enzalutamide has been approved but it should be available to all men with advanced prostate cancer. The restriction is very bad for men who have received other limited treatment. Abirateron is the only other drug available to them. At such a difficult time this adds significant extra pressure and worry onto the patient. For clinicians the decision is very difficult as they won't be able to tell in advance which course of treatment will work better for the individual.If the wrong choice is made then all other avenues will be shut off for the patient. Making the wrong choice will literally be a FATAL mistake.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It's good to hear that enzalutamide has been approved but it should be available to all men with advanced prostate cancer. The restriction is very bad for men who have received other limited treatment. Abirateron is the only other drug available to them. At such a difficult time this adds significant extra pressure and worry onto the patient. For clinicians the decision is very difficult as they won't be able

	to tell in advance which course of treatment will work better for the individual.If the wrong choice is made then all other avenues will be shut off for the patient. Making the wrong choice will literally be a FATAL mistake.
Section 9 (Sources of evidence considered by the Committee)	

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am in the early stages of cancer investigation. I'm shocked to learn that there is a treatment available in Scotland that is harder to obtain in England. I'm 51 years old, have been employed constantly since 17 and have paid into NI since. I have 16 years contributions ahead of me. Should I be denied / have difficulty obtain every possible treatment? Wait until it happens to you! This is scary and every effort should be made to keep me alive.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I agree with the comments of the Men United team. ? It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. ? This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. ? This complicates the situation for men at an already difficult time. ? This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. ? The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	other
Other role	[redacted] Bridgewater Community Healthcare NHS Trust
Location	England
Conflict	no
Notes	Trade Union Health and Safety Coordinator
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Many men with prostate cancer will be pleased that enzalutamide has been approved. However restrictions placed on its usage is disturbing for men who already have limited treatment options and this makes the situation more tense for men, their spouses and families.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This blatant u-turn is most unfair to those of us with advanced prostate cancer. Our options are very limited anyway, so please reconsider your decision.

Role	Carer
Other role	Wife
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	Regardless of side effects, my husband will try any drug to lengthen his already shortened potential lifespan. He is only 61 and had fought prostate cancer for 9 years. He has withstood Docetaxel and Cabazitaxel. Abiraterone has been his most successful treatment to date. He couldn't wait for Enzalutamide. Why not allow the manufacturer of Enzalutamide some discretion in making Enzalutamide available on compassionate grounds to post Abiraterone patients? Perhaps at a further discounted price? This would be a win-win situation for the manufacturer. It would provide them with valuable clinical data in the absence of a lengthy and costly clinical trial.
Section 4 (Consideration of the evidence)	The Committee may not make recommendations based on equalities/social value judgements but why should men who have taken abiraterone because it was the only available next treatment for them be penalised for needing further treatment before enzalutamide was made available? Sorry - you can't have it because it wasn't available when you needed it and now you need it you can't have it because you had what was available then ....! Grossly unfair!
Section 7 (Proposed date of review of guidance)	What is the point in giving a review date? The men who need it now and in the near future will have deteriorated or be dead.
Section 8 (Appraisal Committee members)	Where are the hospital oncologists who are dealing every day with men suffering this devastating disease and having to tell them they can't give them Enzalutamide because unfortunately they were the lucky ones to get Abiraterone when they needed it? The oncologists know their patients - let them have more of a say!

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have aggressive PCa, to date only chemo has had any posiitve effect on my cancer. Abiraterone has not worked for me as it has for many others and you are denying me a possible option of help in fighting my cancer and keeping a father alive for his 3 young children. - It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Good news that enzalutamide has been approved, as it?s a n effective drug. It would be great if it was available for to men with advanced prostate cancer, as a friend's Dad has recently been diagnosed. The restriction means that him ,and his family will face difficult decisions - at a time that is already stressful and upsetting, as he already has limited treatment options available. As abiraterone is the only other drug available to men in the advanced stages of prostate cancer. It also makes the decisions about the treatment pathway difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction. This seems fair and humane.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I think all (effective) treatments should be available for use at the discretion of oncologists and not subject to financial constraints.
Section 2 (The technology)	The treatment should be made available but patients' reactions carefully monitored.
Section 4 (Consideration of the evidence)	The only consideration should be the overall best interests of the patient.

Role	Patient
Location	England
Conflict	no
Notes	Have advanced prostatic cancer with widespread bone metastases. Am curently being treated with Zoladex subcutaneous 3 monthly injections and been recently enrolled on STAMPEDE trial and am awaiting my first prescription of Abiraterone.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am scheduled to receive abiraterone as part of a voluntary clinical trial (STAMPEDE). I may or may not benefit but future patients will benefit from such trials. By indicating that abiraterone treated patients will be denied access to enzulatamide is effectively an advice to patients not to enter such trials as STAMPEDE. I understand this approach is not being followed anywhere else in the world or even in Scotland. Am I and other similar sufferers not as entitled as anyone else to have an opportunity to extend our often very active lives perhaps to the extent where a future actual cure might be available? NICE explains that it is minded to take this stance as enzalutamide has not yet been trialled in abiraterone treated patients, but this is not evidence that it won't work. There are many thousand of drug therapies for different conditions. Is NICE saying that each and every one of these must be trialled with enzalutamide before it can be recommended? There are thousands of experienced health professionals here in the UK and around the world who do not share NICE's approach on this matter. Can their collective compassion and wisdom really be in error? Please reconsider.
Section 2 (The technology)	Please note that whilst expensive at present, in terms of the possible health outcomes and the expected number of candidates for this treatment, this is unlikely to place a major burden on NHS resources.
Section 3 (The manufacturer's submission)	These QALY costings have broadly already been accepted in other jurisdictions.

Section 4 (Consideration of the evidence)	Once again the prohibition of abiraterone treated patients is raised without supportive evidence and contrary to widespread medical practice in other health services.
Section 8 (Appraisal Committee members)	I may be mistaken, but it does not become immediately apparent that amongst the excellently qualified medical and nursing personnel there were any consultant urologists or prostatic oncologists on the assessment team.
Section 9 (Sources of evidence considered by the Committee)	It is noted that whilst the no doubt excellent opinions submitted by the above were listened carefully to, they had no voice in the actual decision produced by NICE.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s good that enzalutamide has been approved but the restriction is bad news for men who already have limited treatment. Where abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	You have the option of prolonging lives. It is not fair or human to say part of the UK can be given this drug and not others.
Section 2 (The technology)	How much is yours, mine or any other persons life worth ?
Section 3 (The manufacturer's submission)	Just one life saved or prolonged has got to be worth it no matter how many test are carried out.
Section 4 (Consideration of the evidence)	You have the evidence, please don't play god with peoples lives.
Section 5 (Implementation)	Implement it NOW. PLEASE
Section 7 (Proposed date of review of guidance)	You hold peoples lives in your hands, don't miss this chance.

Role	Public
Location	England
Conflict	no

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The availability of the drugs for men in England should be made avaialable.

Role	Patient
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a young, fit and superficially healthy 63 year-old with metastatic hormone-relapsed prostate cancer. I have excellent quality of life with no pain and no side effects apart from minor tiredness and reduction in motivation. On 27 January I had my 10th and final infusion of docetaxel. It is impossible to forecast the future but my prognosis is not good. I am looking forward to supporting my wife into the future by working on the house and farm for as long as possible. The options available as my cancer progresses are decreasing and I had anticipated that both abiraterone and enzlutamide would be available to me when I need them. We know that different drugs work in different ways on different people, and it is not known if/how they work on an individual until they have been tried by that individual.
Section 5 (Implementation)	I am really disappointed to hear that NICE currently intends that I should have to make a choice between the two of these medications. This means that I will have to make a purely arbitrary decision by tossing a coin to decide whether to have abiraterone or enzalutamide. Ideally, I would like both drugs to be available when I need them, this will extend my useful life supporting my wife for as long as possible. If this is not possible, then I consider that I should have the opportunity to try one of these two drugs to see if it works and if I have any side effects, before making the decision for one or the other. Thank you.

Role	Patient
Location	England
Conflict	no
Notes	I have had prostate cancer and I am currently being monitored
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I disagree strongly with the recommendation in section 1--Enzalutamide should be made available at the earliest possible time to enhance cancer victims survival rates
Section 2	Cost should not be a prohibiting factor we are talking of saving

(The technology)	lives and you should not put a cost on that fact.
Section 3 (The manufacturer's submission)	Enzalutamide reduces the risk of death by 36.9% this alone should mean that it is made readily available
Section 4 (Consideration of the evidence)	Evidence exists that proves that enzalutamide can extend life -- this should support its wider usage.
Section 5 (Implementation)	I agree totally with section 5.2

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	treatment should not be linked to not having received abiraterone. Given the paucity of treatments available all treatments should be available to men at this late stage

Role	Patient
Location	England
Conflict	no
Notes	As a prostate cancer person I think it is essential that every avenue is kept open for men to maintain their dignity in being helped to live as long as possible. The impact on families is incalculable and must be factored in
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Quite simply - the rationale for this decision is irrationally discriminating
Section 2 (The technology)	What price life for a family?

Role	Patient
Location	Wales
Conflict	no
Notes	I would like to object to the decision of NICE to halt the availability of Enzalutamide for men who have already had a course of Abiraterone. I ask that this decision is reversed so as to allow those who do not benefit from the Abiraterone to have a second chance of life, even if that is short. I appreciate that the cost, about Â£26000, is not insignificant, but what price can be put on life and being with your family for longer. I am presently undergoing radiotherapy and therefore am not at that stage, but I can imagine how someone would feel in that position. Whoever makes that decision, can I ask what you as a human being would want and feel if in future you were a patient at that stage in your treatment. [redacted].
Comments on individual sections of the ACD:	
Section 1	It is hardly right and fair that the drug will only be available if a

(Appraisal Committee's preliminary recommendations)	discount is offered, though I can see that the committee wishes to pressurise the manufacturer. Also if the patient has not benefited form abiraterone it must surely be logical to treat with enzalutamide instead.
Section 2 (The technology)	There can be no barrier to providing enzalutamide if a definite discount is available. It would be denying life to the patient.
Section 3 (The manufacturer's submission)	I agree that enzalutamide is a cost effective solution if abiraterone is not successful.
Section 4 (Consideration of the evidence)	I do not understand why, if the results show the cost effectiveness of enzalutamide in populations where other drugs are relatively ineffective, it cannot be prescribed for those smaller numbers of patients. Indeed the decision seems perverse.
Section 5 (Implementation)	This seems contrary to the proposed procedure.
Section 6 (Related NICE guidance)	No comment on the information.
Section 7 (Proposed date of review of guidance)	No comment on the date.
Section 8 (Appraisal Committee members)	No comment regarding the members.
Section 9 (Sources of evidence considered by the Committee)	No comment regarding the sources.

Role	other
Other role	HM Forces
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that this is a fair recommendation with the treatment of prostate cancer.
Section 2 (The technology)	A fantastic piece of equipment that needs to be incorporated in the health care provision for men
Section 5 (Implementation)	This needs implementing now
Section 7 (Proposed date of review of guidance)	It is essential that this treatment is brought into use in an attempt to save lives
Section 8 (Appraisal Committee members)	Good luck

Role	NHS Professional
Other role	widow ...due to prostate cancer
Location	England
Conflict	no
Notes	when my husband was diagnosed at 53 the disease had already spread throughout the body he was asked to take part

	in trials but what we really needed was access to all cancer fighting drugs available ..i believe there should be MUCH MUCH MORE publicity and information in the media about this awful silent killer even young men in their 20`s get this disease its time we fought back hard so no one else loses their son ..brother husband or father to this debilitating disease that robbed my granddaughters of a granddad they will never meet.
Comments on individual sections of the ACD:	
Section 2 (The technology)	would you deny this treatment to your loved one because of cost,and why is it so expensive ,WHO GAINS

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is totally unfair. Too many people die from prostate cancer. You cannot act to prevent us getting the best treatment available. It could be you next.

Role	other
Other role	Tax payer
Location	England
Conflict	no
Notes	It is incredible that NICE is discriminating against 50% of the population - men. Men and women who suffer from breast cancer rightly have access to many drugs and treatments. Why are you withholding opportunity to life from men?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	You seem to want to let the illness progress after inferior treatments have failed and risk the cancer developing to the point where it can't be successfully beaten. Please explain excatly what the agreed discount is and give comparisons to drugs used to treat breast cancer.
Section 2 (The technology)	Please tell me I have misunderstood the patient access scheme. NICE are proposing health for the rich. REALLY.

Role	other
Other role	Sufferer from Prostate Cancer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This approach is completely illogical and is answering the wrong question. The real way to do this analysis is to do a controlled trial comparing enzalutamide with abiraterone in a controlled trial without the restrictions above. I know from actual experience that the outcome with different patients using the same treatment regime can be completely different. I realise that there is a role for cost effectiveness in todays health service BUT there are little enough drugs in the armoury for

	treating advanced prostate cancer so clinitions should be free to use their clinical judgement without restriction until sufficient evidence is available to determine the actual resilts. The decision does not allow sufficient weight to the effect on patients and there would appear to be some non financial advantages of enzalutamide which are not given sufficient weight by the proposed approach.I note that the proposed restrictions do not apply in Scotland. This appears inconsistent and discriminatory to patients living in England. Having read the report in full it is over complicated. An unbiased executive summary should be made available to all concerned parties for comment
Section 8 (Appraisal Committee members)	There do not appear to be any prostate cancer sufferers in this group. It is time the medical profession realised that there are plenty of us with audit and statistical skills developed in other fields who would be able to understand and comment on the statistical validity of these arguments. The problem with this type of analsis is that the results are highly assumption dependant

Role	Public
Location	England
Conflict	no
Section 7 (Proposed date of review of guidance)	If this drug extends men's lives, I find it disturbing that it would be removed from use. Disgusting that cost once again is chosen over life.

Role	Patient
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have locally advanced prostate cancer. My family and I await my 3 monthly PSA test with trepidation. My quality of life has declined since my prostatectomy but I am very grateful to be alive. It is wonderful news when medical developments extend and improve quality of life. It was wonderful when Enzalutamide was approved. I understand that all our lives are finite but I am distressed that an either/or situation has occurred which is intolerable for both the clinician and patient. Effectively my consultant will have to blindly guess on my life. Until there is a clear indication which drug is appropriate for an individual patient then both drugs should be freely available. Clearly the Scottish Medicine Consortium believe this to be the case.

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

Section 1 (Appraisal Committee's preliminary recommendations)	I am pleased to see that Enzalutamide has been given limited approval. However I am very disappointed with those limitations. I am 65 with advanced prostate cancer. Given my very limited options and life expectancy I would hope that all reasonable ways of increasing my available days would be afforded to me. Enzalutamide and Abiraterone work in different ways and we do not yet have a great deal of evidence of how being treated with one effects being treated by the other. So being denied one followed by the other seems unreasonable. Yes it is expensive but given how a lot of men, myself included, will die young of prostate cancer and hence be of no burden to the health service in old age I think it only fair that we are given the options of such treatments whilst still around to benefit from them. I feel particularly bitter about this as, to further medical research; I was a volunteer on the stage III trial of Enzalutamide against Bicalutamide. As it is a double blind trial I still do not know what I was on but to be told that if I was on Bicalutamide and now chose to be treated with Abiraterone I will then be denied Enzalutamide is devastating. Please remove this limitation.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have had chemotherapy, which made me very ill, and abiraterone, which stopped having any effect after 3 months. My PSA is flying up to 97. Enzalutamide is my only hope to stay alive. Please delete the caveat preventing my use of enzalutamide. Without it I face certain death.

Role	Patient
Other role	Committee member, Oxfordshire Prostate Cancer Support Group
Location	England
Conflict	no
Notes	I had a radical prostatectomy in 2010.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Whilst it is positive that enzalutamide has been approved for use, the restriction placed upon it (i.e. that it cannot be used on men for whom abiraterone has failed) effectively denies the drug to a large number of men for whom it was designed. If health professionals have to make a clinical decision between these two treatments, rather than being able to follow one with the other if appropriate, they will be limited in the effectiveness of the decisions they can take. It is essential that this restriction should be removed, allowing men the option of using enzalutamide where abiraterone has not proved effective.

Role	Patient
Other role	Chair Prostate Cancer Cardiff Support Group
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The restriction involving men who have previously taken Abiraterone is unfair to patients with terminal illness.
Section 2 (The technology)	The value of life is incalculable. Every month counts, particularly when death approaches.
Section 3 (The manufacturer's submission)	The evidence of effectiveness of the drug is compelling.
Section 4 (Consideration of the evidence)	A terminally ill patient hopes that society will support him even if the cost is substantial. We should not deny him the fulfilment of this hope.
Section 5 (Implementation)	Doctors should not have to consider the previous supply of abiraterone as a restriction to their subsequent decisions about the best further treatment option.
Section 6 (Related NICE guidance)	Fortunately NICE has previously approved non-restrictive treatment options for prostate cancer.
Section 7 (Proposed date of review of guidance)	The sooner a positive outcome is reached for the patients concerned the greater their chances of fulfilment of last hopes.
Section 8 (Appraisal Committee members)	An impressive body of medical experts. Surely there is a good hope of a positive outcome to this project.
Section 9 (Sources of evidence considered by the Committee)	I am delighted to see that patient experts have provided evidence.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have metastatic prostate cancer. It is good news that NICE has approved enzalutamide. However, I am very concerned at the restriction that the patient should not have had abiraterone. The drugs work differently and men and their doctors will have to make the difficult decision which option to go for at a time when there are very limited treatments available. There has been little research done into treatments for advanced prostate cancer and there is insufficient evidence to know which drug will better target the disease for the particular patient. Doctors cannot tell in advance. I hope that NICE will remove this restriction which is unfair to men who have such limited treatment options.

Role	Public

Other role	
Location	England
Conflict	no
Notes	Prostate cancer runs in my family, I am worried there will be no suitable drugs available if god forbid I get it.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	please make the drugs available.

Role	Public
Location	Scotland
Conflict	no
Notes	Aren?t I a lucky bloke ? I live in Scotland ? not England, where prostate cancer patients are discriminated against by NICE. It seems down in the benighted south, prostate cancer patients have, unless they have not had abireterone before, been denied enzalutamide after they've had chemotherapy. This is a blatant denial of the basic human right to life. Surely it can?t be just a matter of cost to the NHS ?. Strewth !, they will take off peoples? tattoos on the NHS without a thought of the cost. So why not give a prostate cancer sufferer that little bit more possible life. Or is it just a case that men get prostate cancer, not women !
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	You do not say WHY you have put in the abiraterone condition
Section 2 (The technology)	So it is about money ! How about the money men have paid in to the social security system over a lifetime of probably only rarely using the NHS until the time they get seriously ill with prostate cancer ? This is a disgrace !
Section 3 (The manufacturer's submission)	So .. it works, but NICE just don't want to pay for it ! A disgrace
Section 4 (Consideration of the evidence)	This section is gobbledigook. And why discriminate by bringing in "transgenders" ? people are people !
Section 5 (Implementation)	The key word here is "cost". What a disgrace
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	Why wait more than a year for this important review ? Get on with it !
Section 8 (Appraisal Committee members)	Don't see many actual prostate cancer sufferers on that list !

Section 9 (Sources of evidence considered by the Committee)	And how many prostate cancer sufferers ? Aren?t I a lucky bloke ? I live in Scotland ? not England, where prostate cancer patients are discriminated against by NICE. It seems down in the benighted south, prostate cancer patients have, unless they have not had abireterone before, been denied enzalutamide after they've had chemotherapy. This is a blatant denial of the basic human right to life. Surely it can?t be just a matter of cost to the NHS ?. Strewth !, they will take off peoples? tattoos on the NHS without a thought of the cost. So why not give a prostate cancer sufferer that little bit more possible life. Or is it just a case that men get prostate cancer, not women !

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Effectively forcing people to make a choice between treatments at such a difficult time seems to be grossly unfair and motivated purely by the desire to save money.

Role	Patient
Location	England
Conflict	no
Notes	I am a patient currently taking enzalutamide after treatment with docetaxel and cabazitaxel. This is funded by private medical insurance. Docetaxel treatment had to be curtailed after 5 cycles due to long nerve damage. Cabazital had to be stopped after 8 cycles due to it failing and long nerve damage This also had to have the dosage reduced due to other gut issues. enzalutamide is working with little or no side effects and the lack of steroids is brilliant. The hope this drug and abiraterone give me is significant. I understand NICE concerns but with the rapid development of new and improved drugs any drug that extends my life expectancy gives me psychological peace and has to be worth the cost. I am surprised that this form and my details are not HTTPS. I would not normally fill in a non secure form but I feel so strongly about this issue.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	More wide spread prescribed and usage allows the NHS and private health insurance companies will no doubt help reduce the costs.

Section 2 (The technology)	Although the costs seem high in comparison to other treatments for other conditions i.e. Obesity, alcoholism, drug addiction and surgery for body image changing these cannot be compared to life extension drugs.
Section 4 (Consideration of the evidence)	More wide spread prescribed and usage should allow the NHS and private health insurance companies to negotiate a reduced cost.

Role	NHS Professional
Location	England
Conflict	no
Notes	Make drugs available to all in the uk!

Role	other
Other role	A very concered 65 year old
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This decision is very unfair and will mean that men and their doctors will have to make a really difficult decision about which treatment to try at an already very difficult time. Men with advanced prostate cancer do not have a lot of treatment options, and we don't think NICE should be placing this restriction on men.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	**********Surely everyone deserves the best available treatment - The right of life is absolute and denying young men often with young dependants, of Enzalutamide, is cruel and unjust. Yes I acknowledge there will be instances where because of contributory factors, it would not be ethical or good value to prescribe this drug , however surely every case should be judged case by case, rather than pulling the rug from under the feet of young and old men alike. There should be an element of trust, between NICE and Uncology consultants when making "informed decisions" re suitability and criteria to prescribe this drug, so those whom would benefit from Enzalutamide is not only prescribed Abiraterone but also has the added addition of Enzalutamide. This is no longer an old mans, disease, there a many young men whom have hormone-relapsed metastatic prostate cancer - whom lives depend on this drug - in the absence on there being a cure My husband is 49 years old, we have an 11 year old child. By

	potentially depriving him of Enzalutamide, you are depriving him of the choice of prolonging his life and signing his death warrant.
Section 2 (The technology)	********** 2.1: Every drug potentially has side effects.....when it comes to prolonging a persons life, that person - especially young will be prepared to endure side effects in the knowledge that gaining precious time. 2.3: Should a cost be put on anyones life.....it is like putting a financial bounty on their head. It is good that this drug has been developed but at what cost.....if it isn't prescribed to all who would benefit from it. **********
Section 3 (The manufacturer's submission)	**********Concerned that the median age was 69....although no one should have the right to deprive life. Each case should be considered on an individual basis..... Did the Manufacture supply NICE with a break down of number of men that took part in the trial - in each age group Ie: 40 - 45 yrs , 45 - 50 yrs etc - because it would be interesting to know the comparison of "young men" on the trial - taking Enzalutamide compared to older men - whom are more likely to have other illnesses / conditions which could potentially impact on test results. Why did the manufacture chose to exclude Mitoxantrone as a comparator for Enzalutamide - Mitoxamide was previously part of the standard care for men with Metastic Hormone Relapsed Prostate Cancer ??? Surely if Mitoxantrone improved quality of life ....it makes sense for it to be used and go hand in hand with a drug like Enzalutamide which prolongs life. There appears to be no suggestion from the manufactures that Enzalutamide didn't tolerate Mitroxantrone, it appears that it was just dismissed by them - which is questionable. .....
Section 5 (Implementation)	**********IIt just doesn't make sense - it is drug which is deemed suitable to prolong life - in addition to abiraterone can only be a good thing. if NICE are restricting the use of Enzulutamide, why should patients suffering from this or any other disease partake in clinical trials if the availability is restricted.
Section 7 (Proposed date of review of guidance)	as per above
Section 8 (Appraisal Committee	**********

members)	********** No scientist, no wife, no consultant, no nurse , no one knows what it is like to ensure this disease because we are not suffering from it. We only see the effects. We ALL are in effect signing a persons death warrant - by depriving persons who could be benefited by BOTH drugs of their life, can't be right. I don't want that on my conscious - Do you ??? please can you tell me what member of the NICE project team are suffering as a result of this decision making. I am the wife of a male whom is likely to be affected by this decision - I see the effects of the disease - is it too much to ask???
Section 9 (Sources of evidence considered by the Committee)	**********I am concerned that lead consultants and trial nurses from Uncology Depts in the UK whom have been involved in trials of Enzalutamide was not involved in the decision making. By reversing this decision and making it the responsibility of the Lead consultant in Uncology Dept to judge each person on an individual basis would not only benefit the individual but also show the General Public that Prostate Cancer is beginning to be treated like other Cancers. I do not know of any other Cancer where NICE or the medical profession basically waits for an elderly person to die of old age or another unrelated matter - rather than treat it. To allow the Cancer to spread and become uncontrollable in a YOUNG man is unforgivable. ONLY NICE can reverse this and make it right. If this decision was reversed - NICE could impose stringent guidelines re implementation - having regard to all factors and quality of life. I thank you for taking the time and trouble to read this.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	When prescribing, doctors can't know whether enzalutamide or abiraterone will work better because of their different modes of operation. Thus if the wrong decision is made, use of an ineffective drug may preclude later use of one which could be effective. Use of enzalutamide has been approved without this particular restriction by the Scottish Medicines Consortium - a different conclusion based on the same evidence would be inconsistent.

Role	Patient
Location	Wales
Conflict	no
Notes	I am at this time on Prostap.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	this is cutting off a mans last life line

Role	Patient
Location	England
Conflict	no
Section 4 (Consideration of the evidence)	There is emerging evidence of the efficacy of enzalutamide post abiraterone. I can see no evidence that the committee referenced these data. Please see Andres et al. EUROPEAN UROLOGY 65 (2014) 30?36 Enzalutamide is cheaper than Abitaterone and it would not seem perfectly reasonable to allow oncologicts to offer this less expensive better profiled drug to their patients. In Scotland they can and do. How can NHS E&W justify a contrary position to its UK neighbour?
Section 9 (Sources of evidence considered by the Committee)	See my comments Re. section 4

Role	Patient
Location	England
Conflict	no
Notes	I am a current user of enzalutamide and the benefits I am getting are just unbelievable and must be made available to the maximum number of people living with prostate cancer.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	As a patient who is already receiving the incredible benefits of enzalutamide a drug that has changed my life, it is essential

preliminary recommendations)	that this drug is made available to maximum number of men with prostate cancer no matter where they live or what other drugs they have been taking in the past or may have to take in the future.
Section 3 (The manufacturer's submission)	The evidence speaks for itself.
Section 4 (Consideration of the evidence)	A restriction on patients who have have had the use of other types of drugs that happened to be licensed prior to enzalutamide is not acceptable.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a patient who's cancer has not yet advanced to needing either abiraterone or enzalutamide but when it does I want to try either or both drugs to see which one suits my cancer and bio-chemistry best. No clinician can tell me this without trying the drugs. I object to the exclusion of prior abiraterone treatment.
Section 2 (The technology)	No comment
Section 3 (The manufacturer's submission)	No comment
Section 4 (Consideration of the evidence)	No comment
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No comment

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	You are asking clinicians and patients to make decisions on treatment without the necessary information. Because of the historic underfunding of research into Prostate Cancer no one knows which treatments will work for each patient until they have been tried. You are also reducing the hope of patients with Advanced Prostate Cancer. Enzalutamide represents one last possibility of extending life.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	This decision is very unfair and will mean that men and their doctors will have to make a really difficult decision about which treatment to try at an already very difficult time. Men with advanced prostate cancer do not have a lot of treatment options, and we don't think NICE should be placing this restriction on men.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Do not agree
Section 4 (Consideration of the evidence)	Not happy with this conclusion

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a patient with prostate cancer any atempt to restrict any medicine that could help is tantamount to a form of genicide
Section 2 (The technology)	Again as a patient I can only say that what price is life worth ?
Section 9 (Sources of evidence considered by the Committee)	I am not a doctor but the decision to have any restrictive practice is wrong

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel strongly that enzalutamide should be made available to patients who have NOT already had treatment with abiraterone, at the doctor's discretion, as is standard in Scotland. It should be up to the patient's clinician to decide which drug will work best, particularly when time is limited in an advanced case of prostate cancer.

Role	Carer
Other role	volunteer
Location	England
Conflict	no
Notes	My husband [redacted] was diagnosed with advanced metastatic castrate resistant prostate cancer 2.5 years ago.

	After one year on standard hormone therapy the cancer came back in the hip/pelvic area. Then a course of radiotherapy again standard treatment. After a year there were new small tumours found in several areas. His PSA was still low. We are in a fortunate position to self fund or have treatment funded through private insurance. He has been on denosumab injections licensed but not approved by NICE for prostate cancer. For 6 months he has been doing well and shows signs of bone regeneration. To read about drugs that can be used in the future but again not approved by NICE for those that can afford it is simply evil. Advanced castrate resistant prostate cancer is deadly. This is not an orphan cancer which is incredibly rare. This is a cancer that kills one man per hour every day of every month of every year. The treatments available 2.5 years ago had not changed for decades. For the first time there is hope for men with the new drugs and it looks like less of them will be available in England. If this drug is no longer made available there is no hope that drugs such as denosumab or alpha radon will ever be approved.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	why do men have to use this drug as a last resort instead of front line. Docetaxel has not been a life saver for this cancer. In other countries Abiraterone is the front line treatment. FDA is considering Enzalutamide as another frontline treatment before Chemo.
Section 2 (The technology)	With the right negotiation on price why is there even a question on this. There is an advantage to this drug as it doesn't require steroids.
Section 4 (Consideration of the evidence)	The following sentences at the end of each paragraph speak for itself. The Committee acknowledged that enzalutamide would be welcomed by clinicians and patients. It therefore concluded that enzalutamide could be recommended as an option for treating hormone‑relapsed metastatic prostate cancer in adults, only if their disease has progressed during or after 1 docetaxel-containing chemotherapy regimen, and only if the manufacturer provides enzalutamide with the discount agreed in the patient access scheme. It therefore concluded that enzalutamide fulfilled the criterion for life extension. With all the positives why force men and their families into making a choice of either or?

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The recommendations in section 1 appear limit options available to treat patients. This restriction on patients previously treated with abiraterone is; out of line with Scottish regulations, gives patients less options and leaves doctors with hard descions. Let's Fight Cancer!

Role	Public
Location	England
Conflict	no
Notes	I recently approached my doctor to see if, as in the case of Women, there was any form of men's health screening and was shocked to be told they NO LONGER carried out mens health checks. I raised the issue that I was concerned about potential symptoms regarding prostate cancer and was told that the attitudes to this cancer were changing and blood tests were no longer carried out routinely to test for this insidious disease because of false positives and also that invasive tests even where a positive blood result occurred were not recommended as the normal life expectancy may cause death before prostrate cancer.... WHAT????. Men already have a shorter life expectancy than women, most work their entire lives without a career break and throughout their lives pay the bulk of the taxes/NI that fund NHS treatments, yet they are denied basic screening and treatments for one of the major killers of men, whereas women are provided with routine cervical & breast screening, operations and drugs to extend their lives. Women are also now being offered IVF on the NHS, yet lack of pregnancy most definitely will not cause death and the giving of IVF absolutely does not save or extend a life, unless the woman is suicidal, in which case enabling her to become pregnant is probably the most dangerous thing to do for her potential child. How can NICE possibly justify withholding enzalutamide where abiraterone has previously been used as this clearly restricts a doctor's treatment options at both the earlier and later stages and could well deny an extension to a mans life after he has already been denied early detection and treatment. Where is the moral compass in all this?
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is a very positive thing that Enzalutamide has been recommended but I cannot understand why this is only on the proviso that Abiraterone has not previously been used. Perhaps NICE could make more effort to clarify. This proviso can only reduce the options available to doctors and patients at a time where the lack of funding for prostate cancer research means there are very few effective drugs available and one assumes that to prescribe Enzalutamide is a clear acceptance that Abiraterone has not been effective. I believe the Scottish Medicines Consortium looked at the same evidence and have approved Enzalutamide without this restriction. I can only question why and ask NICE to reconsider their decision and allow both drugs to be used without restriction. Finally, NICE will automatically deny all those currently using

	Abiraterone as a treatment from access to Enzalutamide as a direct result of stating that Enzalutamide cannot be given where Abiraterone has been used - this is clearly not fair on those people and creates a two tier treatment process denying existing patients the opportunity to take Enzalutamide.
Section 2 (The technology)	The side effects would have to be considered/compared to the severity of the disease being treated and monitored accordingly by the clinician. A number of patients would probably opt not to take the drug or to stop taking it early on if the symptoms were too severe, accepting a shorter but better quality of life which could naturally result in a financial saving. Whatever, I would argue that to deny access to enzalutamide on the grounds of having previously used abiraterone is harsh and unfair given that this is an end of life treatment and therefore would not be likely to be taken for a particularly protracted period, although one can only hope it is found to prolong life far more than the trials suggest. Only allowing the use of both drugs would determine this. It should be remembered that the generation taking this drug have in the main contributed financially throughout their entire lives, so morally have earned the right to treatment.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Everyone should have the right to the best medication available to them regardless of what medication they have had or have not had . No one should play at being God in deciding who should have what ! It should simply be a case of what medication treats the patient best !

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	How can you willingly shorten some ones life
Section 2 (The technology)	What price life
Section 3 (The manufacturer's submission)	Very detailed
Section 4 (Consideration of the evidence)	It's case of why do we put every thing down to finnance
Section 5 (Implementation)	This will be interesting as I do not think it will happen
Section 6 (Related NICE guidance)	No comment
Section 7	As is

(Proposed date of review of guidance)	
Section 8 (Appraisal Committee members)	No comment
Section 9 (Sources of evidence considered by the Committee)	The need to live

Role	other
Other role	relative of sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This restriction is bad news for men who already have limited treatment and makes decisions very difficult for clinicians as enzalutamide and abiraterone work differently. Doctors can?t tell in advance which drug will work better for which men. The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction. This seems to make more sense and is fairer to patients suffering this condition which is massively underfunded in research terms considering the numbers effected. Why should patients suffer simply because their specific condition doesn't attract the research funding despite killing ten thousand men a year in the UK?

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Restricting enzalutamide to patients who have not had treatment with abiraterone is forcing doctors to make a difficult and possibly incorrect choice.

Role	Patient
Location	England
Conflict	no
Notes	I think your proposal as stated is a disgrace. Although admittedly the cost of the drug is expensive how can you possibly say that a mans life if only for 6 months is not worth the cost. As it is I believe prostate cancer is the Cinderella of cancers, men should be screened automatically from the age of 55, we do not do this, now you suggest that even though there is a drug that could extend a mans life towards the end of his journey with prostate cancer and make that extension bearable, you feel it is not worth the cost. You should bow your heads in shame.
Comments on individual sections of the ACD:	

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	There is a real danger that NICE will lose credibility if decisions are taken in England which contradict the approach in Scotland. I am not a medical professional but as someone relatively young (52) with Advanced Prostate Cancer who is currently receiving treatment I have actively engaged the two doctors in my family to help me find a route through the complete spaghetti like mess of treatment options. The restrictions on the prescription of Enzalutamide is confusing as men at this stage, have few treatment options and it over complicates the situation. I understand from the Prostate Cancer message board that Oncology consultants are questioning the validity of this decision and are concerned that cost restrictions are driving the decision making process. I understand that Enzalutamide and Abiraterone work very differently and it is a lottery for doctors to try and second guess which one will work the best for men and NICE are asking Oncologist to take a guess and hope it is right.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should not be limited to patients who have not had abiraterone
Section 3 (The manufacturer's submission)	The results of this drug speak for themselves so should be available to all
Section 4 (Consideration of the evidence)	This drug should be made available post abiraterone due to the minimal side effects and liver toxicity of abiraterone

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This should not be limited to patients that haven't had abiraterone
Section 3 (The manufacturer's submission)	The evidence speaks for itself and this drug should be available to any individual with hormone resistant prostate cancer
Section 4 (Consideration of the evidence)	Enzalutamide should be made available post abiraterone due to the minimal side effects and liver toxicity which could become a problem on abiraterone treatment.

Role	Patient
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel that men who have had abiraterone should have the option of enzalutamide.
Section 2 (The technology)	Agree that enzalutamide should be available under the patient access scheme.
Section 3 (The manufacturer's submission)	I do not feel that the QALY system gives a fair measure of drug benefit.
Section 9 (Sources of evidence considered by the Committee)	Enzalutamide should be available to men who have had abiraterone but developed side effects and were unable to continue with abiraterone. Enzalutamide should given for trial period (6 months) to men who have failed on treatment with abiraterone. Enzalutamide should be offered to men, who are metastatic castration resistant, before chemotherapy.

Role	Public
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should be available as an option from the beginning to all prostate cancer sufferers, whatever stage.
Section 2 (The technology)	none
Section 3 (The manufacturer's submission)	no comments
Section 4 (Consideration of the evidence)	Should be available to all sufferers
Section 5 (Implementation)	none
Section 6 (Related NICE guidance)	none
Section 7 (Proposed date of review of guidance)	none
Section 8 (Appraisal Committee members)	none
Section 9 (Sources of evidence considered by the Committee)	none

Role	Public

Location	England
Conflict	no
Notes	By not allowing men in the UK access to the same drugs as Scottish men you are effectively condemning them to an early death. Would your conscience be clear if it was a member of your family ?
Comments on individual sections of the ACD:	

Role	Carer
Other role	Daughter of prostate cancer patient
Location	England
Conflict	no
Notes	Nothing to disclose
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why exclude patients who have previously been treated with abiraterone when enzalutamide has been shown to be of benefit in both prolonging life expectancy and improving quality of life. These same criteria are not applicable in Scotland and this is unfair.

Role	Public
Other role	
Location	England
Conflict	no
Notes	It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.
Comments on individual sections of the ACD:	
Section 9 (Sources of evidence considered by the Committee)	It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult

	time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If you needed the drug and had no access to private medical insurance, how would you vote then?
Section 2 (The technology)	If you needed the drug and had no access to private medical insurance, how would you vote then?
Section 3 (The manufacturer's submission)	Legislate so that UK approval of newq drugs will in future be dependent on NHS purchase prices being acceptable. In exchange, patents will be extended so that drug developers still earn enough from successful drugs to wish to remain drug developers.
Section 7 (Proposed date of review of guidance)	If it was you, and you had no private medical insurance, would you be so relaxed about waiting until April 2015 or would you think that it was maybe possible to come to a decision rather sooner?
Section 8 (Appraisal Committee members)	evry team member should be dis barred from having private medical insurance
Section 9 (Sources of evidence considered by the Committee)	Is this an exercise in looking democratic or in reaching the right decision?

Role	Public
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	I believe that the NHS will have negotiated a good discount on the price of this drug.
Section 3 (The manufacturer's submission)	This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men.
Section 4 (Consideration of the evidence)	The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction. I believe that men in England & Wales deserve the

	same right to this drug, free from restrictions.
Section 5 (Implementation)	This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them.
Section 6 (Related NICE guidance)	It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer.
Section 7 (Proposed date of review of guidance)	Please review this again urgently and remove the restriction on access to this drug
Section 9 (Sources of evidence considered by the Committee)	I am pleased to learn that Prostate Cancer UK was consulted as they work closely with the men that this decision will affect. Please listen to them and us and remove the restriction on access to enzalutamide.

Role	Patient
Location	England
Conflict	no
Notes	I run the Prostate Cancer Support Group, Tyne & Wear.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The Appraisal Committee's decision has been made too soon as enough time has not elapsed to see how the drug progresses.
Section 2 (The technology)	You can't place cost against life. Patients have to know there are drugs out there and everything possible is being done for them no matter what their age!!!
Section 3 (The manufacturer's submission)	The choice should be personal and be discussed with the consultant treating the patient .
Section 4 (Consideration of the evidence)	WE think that as this is the last resource irrespective of age patients should be given the option of both drugs.
Section 5 (Implementation)	There are other areas in the NHS where money is wasted. When it comes to a life threatening illness costs should be immaterial.
Section 6 (Related NICE guidance)	The notes are too in depth for the individual patient.
Section 7 (Proposed date of review of guidance)	April 2014 would be better.
Section 8 (Appraisal Committee members)	No comment
Section 9 (Sources of evidence considered by the Committee)	No comment

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 6 (Related NICE guidance)	This guidance is very unfair and will mean that men and their doctors will have to make a really difficult decision about which

	treatment to try at an already very difficult time. Men with advanced prostate cancer do not have a lot of treatment options, and I don't think NICE should be placing this restriction on men. The quality of existing procedures and advice already leads to very unfortunate and often painfully depressing outcomes for men and as with so much about the Health Service today decisions are not taken in the best interests of the end user

Role	Patient
Other role	P C UK Volunteer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The "only" stipulation removes removes patient and doctor choice creating obstacles which may not suit all cases?
Section 2 (The technology)	No comment.
Section 4 (Consideration of the evidence)	To me as a patient the side effects of enzalutamide are the more acceptable and vital organ damage reduction most important. Given the above access to this treatment option should be equally accessible to all.
Section 5 (Implementation)	Implementation guidance has too many "get out" opportunities for CCG's

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Men at the end of their life need more options, not fewer. Please reconsider your decision...

Role	other
Other role	Clinical Bioinformatician
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This decision limits the options of those patients where abiraterone is the only other drug available to them. This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why not allow all patients and not exclude those who have had abiraterone

Role	Patient
Other role	[redacted] Tackle prostate cancer (www.tackleprostate.org)
Location	England
Conflict	no
Notes	The attempt by NICE to deny this drug to a large proportion of the men for whom it was designed is a betrayal. There is no clinical evidence to justify it. Indeed, the insertion of this caveat demonstrates either that there is a profound ignorance about the purpose and mechanism of the drug or, more worryingly, that NICE are susceptible to commercial interests of the only competitor to Abiraterone. We call on NICE to reverse this unfair decision.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	There is no evidence that Enzalutamide is any less effective for men who have had Abiraterone, than is Abi itself before men start it. The single trial reported showed that in at least 50% of cases, men who were intolerant to Abiraterone did well under Enzalutamide. If that success/failure rate is OK for one drug (Abi) it should be good enough for the other. The caveat has been introduced, without consultation, for unknown reasons. It is not justified by any clinical considerations and effectively denies the drug to the majority of prospective patients
Section 4 (Consideration of the evidence)	The report of the committee's deliberation shows how preposterous the caveat about pre-use of Abiraterone is. Para 4.21 seems to be the first mention of pre-use of Abiraterone, and it effectively comes out of the blue. No evidence has been presented that suggests the pre-use is counter-indicated. It is as if someone had dreamt up a concern, found that there was no evidence that the concern was groundless and therefore assumed that it was valid. This is so stupid that one has to assume that darker motives were at work.
Section 8 (Appraisal Committee members)	We see do not see the names of any recognised experts in the treatment of advanced prostate cancer, or indeed in oncology.

Role	Patient
Location	England
Conflict	no

Notes	It is wrong that Scotland is able to prescribe this after abertirone but not England.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is wrong that Scotland can prescribe this but England cannot.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It appears that options for patients are being severely restricted at a difficult time for decision making when options should be more open.
Section 2 (The technology)	The average cost when compared with the probability of terminal care/emotional/mental/physical trauma is within reasonable parameters.
Section 4 (Consideration of the evidence)	To take a position where the committee does not recommend this therapy would appear to be based solely on financial grounds and is therefore deeply offensive.
Section 5 (Implementation)	This therapy should appear on the recommended list across the NHS.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	enzalutamide has been approved and recognised as an effective drug -yet you are considering rationing either this drug or aririterone? this is not logical. Scotland has approved. England has not- please explain? I benefited for 18 months on arbiritarone and I consider my life worth the cost. I am very grateful for this. Why are labs doing research at all if drugs that are beneficial are then not used?
Section 2 (The technology)	Commemts as previous

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Whilst I would have to admit that much of what is contained in this document is beyond my level of expertise and understanding, I do feel it important to make the more general point that Prostate Cancer is a condition not well enough understood by the general public and in particular the male population. More funding is required for both promotion and treatment and I strongly object to any options being removed from the toolkit of medical practitioners.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is not reasonable to restrict access to Enzalutamide for patients on the basis of previous treatments received. It forces patients and doctors to make choices at an important stage of treatment which adds to the anxiety and stress of an already difficult time when in fact all treatment options should remain available.
Section 4 (Consideration of the evidence)	There does not seem sufficient evidence over an extended period of time to support the recommendation that Enzalutamide is only available if patients have not already had abiraterone treatment. What studies have been done where patients have received abiraterone and subsequently treated with enzalutamide?

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I don't see why previous treatment with abiraterone should be a condition for receiving this treatment. Options for treatment are very limited at this stage of a patients life and this treatment should be available to all.
Section 2 (The technology)	No comment
Section 3 (The manufacturer's submission)	No comment
Section 4 (Consideration of the evidence)	No comment
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	I am pleased that the committee has decided to consult further on its decision
Section 8 (Appraisal Committee members)	No comment
Section 9 (Sources of evidence considered by the Committee)	No comment

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	I personally feel that the drug should be made available to all who need it, as opposed to only some. The idea of a doctor having to select which patients are to be given the life-extending drugs makes me feel uncomfortable, especially considering the effect on the conscience, mental health, and overall performance of doctors. It is surely better all round, and most importantly for people with prostate cancer, to make the drug available to all people with the disease.

Role	Patient
Other role	Hon. Secretary of a charity
Location	England
Conflict	no
Notes	I have had prostate cancer. I am secretary of a small local PCa charity trying to raise awareness of the disease. In this role I have come into contact with many men who have PCa, including those who have been treated or denied treatment with abiraterone and enzalutamide. Some have died in intense pain having been denied the drug. One of our members was denied abiraterone as he had had chemotherapy, he died in intense pain. He was drinking morphine straight out of the bottle and it had little effect. I could not imagine what he was going through, even though I witnessed it. I am particularly concerned at your prohibition on enzalutamide when the patient has already had abiraterone. I can quote cases where the patient reacted to abiraterone and could not use it, but has been successfully treated with enzalutamide. Your proposed limitation on use would bar such patients from treatment. If this were treatment for women with breast cancer you would not dare put such a bar on its use.If this were treatment for women with breast cancer you would not dare put such a bar on its use. To me it is clear that you are discriminating on a sexual basis, where you favour women?s treatment over that you authorise for men.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have had prostate cancer. I am secretary of a small local PCa charity trying to raise awareness of the disease. In this role I have come into contact with many men who have PCa, including those who have been treated or denied treatment with abiraterone and enzalutamide. Some have died in intense pain having been denied the drug. One of our members was denied abiraterone as he had had chemotherapy, he died in intense pain, he was drinking morphine straight out of the bottle and it had little effect. I could not imagine what he was going through, even though I witnessed it. I am particularly concerned at your prohibition on enzalutamide when the patient has already had abiraterone. I can quote cases where the patient reacted to abiraterone and could not use it, but has been successfully treated with enzalutamide. Your proposed limitation on use would bar such patients from treatment. If this were treatment for women with breast cancer you would not dare put such a bar on its use. To me it is clear

	that you are discriminating on a sexual basis, where you favour women?s treatment over that you authorise for men.
Section 3 (The manufacturer's submission)	Throughout the document you talk about the log-logistic function. Do you mean the log-log function whereby both x and y axes are plotted logarithmically or are you describing a log-linear numbers function. The Weibull function is a log-loglog function where the second axis plots loglog values against simple log values for the first axis. There are several terms in the Weibull analysis and it would be interesting to see if there are any significant break points on the curves. The text is very confusing, I presume deliberately to ensure few comments. It is unclear whether your financial analysis is actually correct and it would seem that there is little cost difference between abiraterone and enzalutamide.
Section 4 (Consideration of the evidence)	Key Conclusion Your first finding prevents its use in the case where a patient has reacted to abiraterone, leaving them without adequate or effective treatment.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe that it should be up to clinicians (and in my case, the consultant oncologist who is responsible for my care) to make the final decision on whether or not enzalutamide is going to be an effective treatment for me. I therefore do not believe it is helpful or ultimately of benefit to place the limitation that entalutamide should not be given to patients who have already been treated with abiraterone. Also, can the committee clarify how many doses of abiraterone should be given for enzalutamide to be precluded?
Section 2 (The technology)	I do realize that enzalutamide is an expensive treatment and that measures are necessary to avoid unnecessary spending on the drug. But the exclusion of patients who have had abiraterone seems arbitrary.
Section 4 (Consideration of the evidence)	I note that "The Committee understood from the clinical specialists that there are few treatment options available for patients with metastatic hormone-relapsed prostate cancer after docetaxel therapy." I find it odd that the committee would wish to limit options.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am an otherwise very healthy 59 year old who was first diagnosed with prostate cancer in 2007. It was very aggressive and my prostate was removed, followed

	by extensive radiotherapy and 3 years of hormone treatment after which the cancer remained undetectable for 18 months. My PSA level is now rising again and I expect to be put back on to hormone medication within a year. I am currently in pretty good shape, however it is inevitable that at some point I will be in the position of having to choose between Enzalutamide and Abiraterone due to the restriction you intend to place on Enzalutamide. This decision is very difficult as Enzalutamide and Abiraterone work differently and doctors can?t tell in advance which will work better for an individual. It is good that Enzalutamide has been approved, however, this restriction is bad news for many men who already have limited treatment options. Also the Scottish Medicines Consortium looked at the same trial data and did not come to this decision. Men in Scotland can have Enzalutamide after they?ve tried Abiraterone. I strongly urge that this decision is re evaluated and the restrictions placed on the use of Enzalutamide removed.

Role	Patient
Location	England
Conflict	no
Notes	I am involved in the clinical trial STAMPEDE
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Did the Appraisal Committee consider patients who are taking part in the clinical trial STAMPEDE? Some patients may have drawn abiraterone as one of the trial's treatments, it seems un fair that this recommendation would bar them from having enzalutamide after they have volunteered for the clinical trial. Was this explained to all patients that taking part in a trial could bar them from future proven treatments?

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This decision may directly effect myself as a patient in this case. It will make options almost impossible to ascertian in due course. will use The Cancer Fund? Also:- - It?s good that enzalutamide has been approved ? it?s an effective drug and we want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only other drug available to them. - This complicates the situation for men at an already difficult

	time. - This makes the decision very difficult for clinicians, as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. - The Scottish Medicines Consortium looked at the same evidence and have approved enzalutamide without this restriction.

Role	NHS Professional
Other role	Cancer Pharmacist
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Totally agree but equally the abiraterone TA (259) requires revisiting to stipulate no prior enzalutamide to ensure consistency as the limited retrospective data for sequential use show a diminished benefit and thus presumably higher costs per QALY

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why should enzalutamide not be given if a person has had treatment with abiratone - and this has failed. Surely each person can react to drugs differently. I think the NHS (and patients) should have the freedom to at least try different combinations of drug therapy.
Section 2 (The technology)	Just can't understand why the NHS has to pay these exorbitant prices, even at the discounted rate. No wonder the generic market in Asia is so big.
Section 4 (Consideration of the evidence)	Doesn't rule out taking this drug as an alternative to abiraterone.
Section 5 (Implementation)	No comment
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	No comment
Section 9 (Sources of evidence considered by the Committee)	No comment

Role	Patient
Location	England
Conflict	no
Notes	I have been living with prostate cancer for 13 years and it is only because of the new drugs that have come along that I am

	still alive
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	You should be offered both drugs
Section 2 (The technology)	the drug sounds good
Section 3 (The manufacturer's submission)	Too complicated to understand
Section 4 (Consideration of the evidence)	Has anybody on the committee had prostate cancer and feared they would die from it. If they had they would recommend the drug
Section 5 (Implementation)	just get on and implement the drug
Section 6 (Related NICE guidance)	sounds okay
Section 7 (Proposed date of review of guidance)	review asap
Section 9 (Sources of evidence considered by the Committee)	you need men who suffer from pc on the committee

Role	other
Other role	Was a carer, my father passed away in 2012
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	- It?s good that enzalutamide has been approved ? it?s an effective drug and I want it to be available to men with advanced prostate cancer. - This restriction is bad news for men who already have limited treatment options ? abiraterone is the only
Section 2 (The technology)	In late 2011 my father was refused abiraterone as he wasn't considered suitable for chemotherapy, imagine my distress when it was decided abiraterone could be prescribed to men who hadn't had chemotherapy. It was too late for my dad, he died in 2012. I would hate the same thing to happen to any one else regarding enzalutamide. Life has been full of 'if onlys' since.

Role	Patient
Location	England
Conflict	no
Notes	I have advanced metastatic prostate cancer
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Enzalutamide has been approved as an effective drug and I'd like it to be available to me when I near the end of my life as well as abiraterone. Apparently the two drugs work differently and it seems unfair if doctors don't know in advance which is

	going to work the best. If the drug is available in Scotland, why not here?

Role	Patient
Location	England
Conflict	no
Notes	I am having treatment, intermittent HT and feel that if treatment is available it shouldn't be a post code lottery, if Scotland can issue this drug then England should. IT should be available to all or none !
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This drug should be available to all
Section 2 (The technology)	Regardless of cost, it should still be available to all
Section 3 (The manufacturer's submission)	Whenever new drugs for cancer are produced there is always a 'cost effective issue', what cost LIFE
Section 4 (Consideration of the evidence)	As I have said before 'What price life', any new drug once it is passed to use should be made available to all.
Section 5 (Implementation)	Are NICE playing GOD ? I know that finance is not bottomless but where a Man's life is concerned stop wasting money on some research to pay for this.
Section 6 (Related NICE guidance)	All these treatments, if our Oncologists think they will do some good then they should be made available

Role	Patient
Location	England
Conflict	no
Notes	I have early prostate cancer (T2N0M0)
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It would be good to know that when/if the time comes to make a choice of drug treatment, that the full choice is available (as in Scotland)
Section 2 (The technology)	I am not comptetent to comment on the technology even though I am a health professional as well as a patient.
Section 5 (Implementation)	Para 5.2 is agreed and I do think that the cheaper option should be tried first (abiraterone). But doctors should have the freedom to prescribe the most effective drug if required especially if there are considerations of side effects and convenience of dosing to consider.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	So prostate cancer sufferers are going to be treated as second class citizens again. Unless the drug is made more widely

preliminary recommendations)	available doctors will nor be able to decide on the best treatment for men.

Role	Patient
Other role	Prostate cancer survivor
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The evidence has been evaluated differently in Scotland.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It?s great that enzalutamide has been approved. It?s an effective drug and it should be available to men with advanced prostate cancer. Men already have limited treatment options as abiraterone is the only other drug available to them. This is not fair and complicates the situation for men at an already difficult time. There are further difficulties for doctors as enzalutamide and abiraterone work differently and doctors can?t tell in advance which will work better for which men. When Scotland looked at the same evidence on the two drugs, they approved enzalutamide without this restriction. Men in England should not be disadvantaged because of their postcode. Medicines should be available to everyone regardless of where they live.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I strongly disagree with this recommendation. Men diagnosed with prostate cancer cannot make an informed decision on rejecting abiraterone in order to use enzalutamide. Neither or both drugs may or may not work. Men face a lottery with treatment anyway, why put their lives at further risk by denying either drug in this senseless u-turn on policy.
Section 4 (Consideration of the evidence)	Abiraterone is still relatively new, more testing is necessary on its effectiveness especially when compared to enzalutamide before men can be denied one in place of the other.

Notes	Dear Sir, I protest strongly against your decision not to allow Enzalutamide to patients who have already been prescribed Abiraterone initially. As you will be aware this will preclude the

	vast majority of men with late stage prostate cancer, almost all of whom will have Abiraterone as part of their treatment as the disease progresses. Enzalutamide is a very effective life extending drug having few if any adverse side effects for the majority of men. I am aware that financial constraints mean that difficult decisions with regard to prioritising drugs have to be made but the evidence in support of Enzalutamide seem to be very clear cut and it should not be denied to any men who may benefit. I write as someone with advanced prostate cancer who fully expects to require both these drugs in the not too distant future.

Notes	Dear Sirs, I have just read that people with advanced prostate cancer that have previously been or are on Abiraterone cannot be given Enzaulamide. This is one of the cruelest things I have ever read. Nobody has the right to play 'God'. Enzaulamide extends life and should be given to everyone who needs it. Yours faithfully, [redacted]

Notes	I have just had a message from FOPS that NICE will no longer be prescribing Enzalutamide after Abiraterone has failed to keep PSA low in patients. CAN THIS BE TRUE?. "Recent trials have proven that using Enzalutamide on men with metastased prostate cancer gives on average SEVENTEEN MONTHS of extra life before the end game starts with Chemo being prescribed. So NICE's recent arbitrary decision to remove access to Enzulatamide, the life enhancer if you had Abiraterone before Chemo, is removing life from those whose lives would on average be extended by 17 months with Enzalutamide. All of North America is using it..Why are you condemning these poor souls to an early death? NICE, you must revert to the proscribing of Enzulatamide as and when the oncologist deems it necessary. Its efficacy could/should be monitored by monthly PSA testing." Enzalutamide (marketed as Xtandi and formerly known as MDV3100) is an androgen receptor antagonist drug developed by the pharmaceutical company Medivation for the treatment of metastatic castration-resistant prostate cancer. Medivation has reported up to an 89% decrease in prostate specific antigen serum levels after a month of taking the medicine. Early

	preclinical studies also suggest that enzalutamide inhibits breast cancer cell growth.[3][4] In August 2012, the U.S. Food and Drug Administration approved enzalutamide for the treatment of castration-resistant prostate cancer. Enzalutamide was discovered by Charles Sawyers who is now at Memorial Sloan–Kettering Cancer Center and Michael Jung at UCLA Enzalutamide has approximately fivefold higher binding affinity for the androgen receptor (AR) compared to the antiandrogen bicalutamide. As opposed to bicalutamide, enzalutamide does not promote translocation of AR to the nucleus and in addition prevents binding of AR to DNA and AR to coactivator proteins. When LNCaP cells (a prostate cancer cell line) engineered to express elevated levels of AR (as found in patients with advanced prostate cancer) were treated with enzalutamide, the expression of androgen dependent genes PSA and TMPRSS2 was down regulated in contrast to bicalutamide where the expression was upregulated. In VCaP cells which over express androgen receptors, enzalutamide induced apoptosis whereas bicalutamide did not. Furthermore enzalutamide behaves as an antagonist of the W741C mutant androgen receptor in contrast to bicalutamide which behaves as a pure agonist when bound to the W741C mutant. Clinical studies Enzalutamide is clinically active in metastatic castration-resistant prostate cancer. PSA level decreased more than 50 percent in 40/65 chemo-naive patients and 38/75 chemotherapy-treated patients.[10] Median time to radiographic progression was 56 weeks for chemo-naive patients and 25 weeks for the post-chemotherapy population.[Medivation conducted an international phase III trial that began in September 2009 known as AFFIRM. The aim of this trial was determine the safety and effectiveness of enzalutamide in patients who have previously failed chemotherapy treatment with docetaxel. In November 2011, this trial was halted after an interim analysis revealed that patients given the drug lived for approximately 5 months longer than those taking placebo. FDA approval was granted in August 2012. So, why is your organization NICE denying this extended life opportunity to British patients?

Notes	The sole reason for the addition of this caveat is cost saving. Since the benefit of Enzalutamide appears to be considerably superior to Abiraterone, men will die a year earlier simply because they were originally given an inferior therapy. Some men have refused chemo - what of them ? Why is it a prerequisite, when plainly Enzalutamide works just as well before & men miss the brutal side effects of chemo ? This whole saga reflects badly on the decision making process within NICE & will erode public confidence in its clinical independence, quite apart from its impact on the dozens of men forced into an earlier grave. [redacted]

	Prostate Cancer Support Group Organizer

Notes	I am writing to you as a 'two year into the journey' prostate cancer survivor, who at the moment is fit, strong and well. It was very good news to learn that NICE have now approved the use of the new drug enzalutamide for the treatment of hormone relapsed metastatic prostate cancer. UK doctors will now have 2 effective drugs for treating patients who no longer respond positively to chemotherapy (docetaxel) treatment. The new enzalutamide drug has a significant advantage over the earlier abiraterone, which after a period of use can have a damaging effect upon a patient's liver. Enzalutamide has also been shown in tests to be more effective than abiraterone with some patients and it can extend life after abiraterone ceases to be affective. The earlier draft proposals by NICE of last October recommended that enzalutamide should only be used after one course of docetexal chemotherapy. I see that the latest recommendation has removed this restriction, which is good, as it means more prostate cancer patients will in future have access to enzalutamide. I understand the latest NICE recommendations for the use of enzalutamide will be adopted by NHS hospitals in England and Wales, but not hospitals in Scotland and possibly Northern Ireland. However. there is one section within the NICE recommendations which I find unacceptable. , If this section is enforced; then OOO's of English and Welsh patients who up until now have been treated with abiraterone, the only drug available and who now need to stop taking abiraterone due to its damaging side effects, will be denied the benefits of enzalutamide, even though by using it, their lives could be made more comfortable and extended by between 5 and 18 months, or even longer. I urge the decision makers at NICE to now reconsider their recommendations regarding eligibility. I know that the cost of enzalutamide is likely to be high (the net price under a patient access scheme is not published for commercial confidentiality reasons). As each of us journey through life, none of us can ever know what the future may hold for us and I recognise it is sometimes rather easier for those in power, during a time of economic hardship, to prioritise the health needs of the young, rather than fund the needs of those who are approaching the end of their lives. However, I would ask you to please remember that the

	men who will most likely benefit from another change in NICE's recommendations, and who will then become eligible to enjoy the benefits of enzalutamide, after previously taking abiraterone, will have paid UK income tax and will have contributed fully to the UK economy throughout the whole of their working lives.

HOUSE OF COMMONS
LONDON SW1A 0AA

31 JAN 2014

Sir Andrew Dillon
Chief Executive
National Institute for Health and Care Excellence
10 Spring Gardens
London SW1A 2BU

29th January 2014

Dear Sir Andrew,

I am writing to raise my concerns about the draft decision published by NICE on 28th January to recommend the prostate cancer drug enzalutamide for use on the NHS only to men who have not already been treated with abiraterone. While I do not wish to intervene in NICE's independent procedures, from information I have been given I am concerned that this decision highlights flaws in the appraisal process that need to be addressed.

It is good news that enzalutamide has been approved for use on the NHS as I believe studies show it can prolong the lives of men with incurable prostate cancer by an average of five months, as well as improve the quality of their lives by reducing pain and other symptoms.

However, I am advised that the restriction around the use of abiraterone is bad news for men with advanced prostate cancer who have limited treatment options. I understand that abiraterone is the only other NICE approved treatment for men with this stage of prostate cancer; ruling out enzalutamide for men who have already received this treatment seems unfair and illogical.

I gather that this stipulation was made because the appraisal committee says they did not see any evidence on the sequential use of these two treatments. However, I am told the Scottish Medicines Consortium looked at the same data and did not place this restriction on the use of enzalutamide. This decision will mean that men in England with advanced prostate cancer have fewer treatment options than men in Scotland!

Additionally, I am concerned about the way this decision was made. The previous draft decision enzalutamide, published in October 2013, did not carry this restriction. If the appraisal committee originally thought the use of enzalutamide should not carry a restriction around abiraterone, why did they change their mind? They have not set out the reason for this which lacks clarity and transparency. The appraisal committee should set out why this new restriction, which was originally not deemed necessary, has been added in through a further draft decision, restricting the use of this treatment and delaying a final decision on the use of this vital treatment.

HOUSE OF COMMONS
LONDON SW1A 0AA

Furthermore, this is a confusing decision which places a huge decision burden on clinicians. At the point where a man has stopped responding to hormone therapy, the clinician now has a complicated decision to make, namely risk excluding a patient from ever having enzalutamide if they think abiraterone would be beneficial, but turns out not to work or to be poorly tolerated by that patient.

I am advised that this is particularly complicated because it is impossible for clinicians to tell which treatment may work better for a particular man until they have tried it. Men and clinicians need options, and this decision restricts their ability to find the treatment that works the best for individual men.

This decision will come as a huge disappointment to those men for whom abiraterone has not worked, as they learn they have reached the end of the road in terms of possible treatments. Unlike those with other common cancers, men with advanced prostate cancer have very few treatment options, due to historic under funding of research.

I hope you will agree that it is therefore very important for NICE's decisions to be made consistently and to take into account the lack of alternative treatment options to ensure that men with prostate cancer are not put at a disadvantage.

I would be grateful if you could respond to the points I've made and share my letter with the relevant appraisal committee to review as part of their public consultation.

Thank you for your consideration. I look forward to your response.

Yours sincerely,

[redacted]

Sir Bob Russell,
MP for Colchester

PLEASE REPLY TO: Magdalen Hall, Wimpole Road, Colchester CO1 2DE
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DATA PROTECTION ACT
Whilst Sir Bob Russell MP will treat as confidential any personal information you pass on, he will allow staff and authorised volunteers to see if this is needed to help and advise you. He may also pass on all or some of this information to agencies such as Government Departments, the Inland Revenue or the local Council if this is necessary to help you with your case. Sir Bob Russell MP may wish to write to you from to time to time to keep you informed on issues that you may find of interest. Please let him know if you do not wish to be contacted for this purpose.

JOHN LEECH MP

Liberal Democrat MP for Manchester, Withington

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03 FEB 2014

Sir Andrew Dillon
Chief Executive
National Institute for Health and Care Excellence
10 Spring Gardens
London
SW1A 2BU

31/03/14

Dear Sir Andrew

I am writing to raise my concerns about the draft decision published by NICE on 28 January to recommend the prostate cancer drug enzalutamide for use on the NHS only to men who have not already been treated with abiraterone. Whilst I do not wish to intervene in NICE's independent procedures, I am concerned that this decision highlights flaws in the appraisal process that need to be addressed.

It is good news that enzalutamide has been approved for use on the NHS as studies show it can prolong the lives of men with incurable prostate cancer by an average of 5 months, as well as improve the quality of their lives by reducing pain and other symptoms. However, the restriction around the use of abiraterone is bad news for men with advanced prostate cancer who have limited treatment options. Abiraterone is the only other NICE approved treatment for men with this stage of prostate cancer and ruling out enzalutamide for men who have already received this treatment is unfair and illogical.

I have seen that this stipulation was made because the appraisal committee says they did not see any evidence on the sequential use of these two treatments. However, the Scottish Medicines Consortium looked at the same data and did not place this restriction on the use of enzalutamide. This decision will mean that men in England with advanced prostate cancer have fewer treatment options than men in Scotland.

Additionally, I am concerned about the way this decision was made. The previous draft decision enzalutamide, published in October 2013, did not carry this restriction. If the appraisal committee originally thought the use of enzalutamide should not carry a restriction around abiraterone, why did they change their mind? They have not set out the reason for this which lacks clarity and transparency. The appraisal committee should set out why this new restriction, which was originally not deemed necessary, has been added in through a further draft decision, restricting the use of this treatment and delaying a final decision on the use of this vital treatment.

Furthermore, this is a confusing decision which places a huge decision burden on clinicians. At the point where a man has stopped responding to hormone therapy, the clinician now has a complicated decision to make, namely risk excluding a patient from ever having enzalutamide if they think abiraterone would be beneficial, but turns

out not to work or to be poorly tolerated by that patient. This is particularly complicated because it is impossible for clinicians to tell which treatment may work better for a particular man until they have tried it. Men and clinicians need options, and this decision restricts their ability to find the treatment that works the best for individual men.

This decision will come as a huge disappointment to those men for whom abiraterone has not worked, as they learn they have reached the end of the road in terms of possible treatments. Unlike those with other common cancers, men with advanced prostate cancer have very few treatment options, due to historic under funding of research. I hope you will agree that it is therefore very important for NICE's decisions to be made consistently and to take into account the lack of alternative treatment options to ensure that men with prostate cancer are not put at a disadvantage.

I would be grateful if you could respond to the points I've made and share my letter with the relevant appraisal committee to review as part of their public consultation.

I will look forward to hearing from you.

Yours sincerely,

John Leech MP

05 FEB 2014

Re: NICE DRAFT GUIDANCE ON ENZALUTAMIDE.

Dear Professor Haslam,

In 'The Daily Telegraph' yesterday, I read an article entitled 'NHS row over new prostate cancer drugs' which described the effects of Enzalutamide, including the fact that it delayed by 80% the progression of advanced cancers that have ceased to respond to other treatments. This seemed like the answer to my prayers, so relevant was its described use and effectiveness to my husband's situation as discussed three weeks ago with his oncologist.

My husband is sixty four years old and suffers from advanced prostate cancer which has metastasised to his bones. Sadly, the draft guidance announced by NICE last week would disqualify him from the opportunity to benefit from this treatment. He was treated with abiraterone for about ten months, it ceased to be effective and his oncologist is considering chemotherapy as the next step. How can NICE, in all humanity, deny access to drugs which 'are even more effective when they are used as soon as a man's cancer develops to the 'hormone-relapsed' stage?'

Last week I read your statement that patients should become more assertive and see themselves as 'equal partners' with their doctors with legal rights. 'When products have been approved for use by NICE, patients have a legal right to those drugs –as long as they are clinically appropriate. The take-up should be much higher than it currently is.' How can you possibly deny access the week after encouraging men to be more vociferous in demanding the most effective treatment from their doctors? How can you reconcile these statements?

For many years of our professional lives, we have both paid income tax at the higher rate. We have not received any benefits and we do not have children. In our retirement, we continue to pay tax, as appropriate, at the 40% rate. I am not saying this should be an automatic entitlement to treatment. I do not think that we are more worthy because we have paid and continue to pay more. I know we have been fortunate and I believe in the equal worth of people. What I am saying is that although we have retired, we are still contributing to the NHS and to state spending in general. I fear that financial considerations might lead to age becoming a significant criterion in qualifications for treatment. Finances

should not be supreme in deciding on the use of new treatments, the effectiveness of which could diminish costs by reducing the use of other treatments.

I implore you to revise your decision. I love my husband and wish neither to see him suffer more and unnecessarily, nor to see him denied the chance to alleviate his condition and prolong his life. How many more people must be feeling the same?

I cannot believe that you have committed your life to this work to support such outcomes. I hope to receive your written response.

Yours sincerely,

Copied to:

Rt. Hon. J. Hunt, Secretary of State for Health.

Rt. Hon. A. Burnham, Shadow Secretary of State for Health.

Mr. S. Tyndale-Biscoe, Hon. Chairman, Prostate Cancer Support Federation.

Mr. M. Euripides, Director of Policy and Strategy, Prostate Cancer U.K.