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

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Where chemotherapy is not likely to be effective due to the spread of prostate cancer throughout the skeleton and lymphatic system the only effective treatment is abiraterone. Â The clinician should therefore be able to continue treatment until it is appropriate to stop.
Section 2 (The technology	The technology is very effective and is good value for money given that the Department of Health considers that the administration of the patient access scheme does not constitute an excessive administrative burden on the NHS.
Section 4 (Consideration of the evidence)	There are insufficient characters allowed to properly address all the issues raised. Â The main arguments used by the committee ignore the ethical decisions made during the trial. Surely it is unethical to continue giving the placebo when the benefits of Abiraterone were clearly Â indicated.
Section 5 (Implementation)	I don't have access to these tools and thus cannot comment.
Section 7 (Related NICE guidance)	No Comment
Section 8 (Proposed date of review of guidance)	No Comment
Date	05/06/2014

Name	[redacted]
Role	Carer
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	"Why Abiraterone Should Be Allowed My husband has advanced and aggressive prostate cancer and has received 8 months of abiraterone before being prescribed docetaxel chemotherapy. I speak from experience when I say: ? Abiraterone was a very effective drug and gave him a good quality of life with no side effects at all. ? At the age of 65, it did keep the PSA down for a significant length of time and it has given him further quality time with his family. ? He experienced none of the weariness and fatigue that he had with other medications for advanced prostate cancer. ? There was no evidence of toxicity outside the acceptable medical range. ? The use of abiraterone has delayed the use of doxetaxel chemotherapy and this medication has proved to be much harder to physically tolerate. ? In contrast, docetaxel chemotherapy has had a very significant impact on his quality of life. He is at a much higher risk of infection and clinicians have seriously considered if the chemotherapy should be delayed for him. ? During the last 18 weeks of chemotherapy he has

	probably felt himself for no more than 7 ? 14 days. ? Many days since starting docetaxel chemotherapy have been spent in the bedroom and he has not dressed himself or got out of bed. ? Abiraterone allowed my husband to live an independent life. Â Once that failed, the tumour in his spine progressed and he is now confined to a wheelchair and also has the debilitating effects of the chemotherapy treatment. ? My husband is fortunate enough to have me as to attend to his needs, whereas many men will be living on their own. They will require a health and social care attendant for many basic everyday functions. ? Not all men are able to be able to travel to a chemotherapy centre without due stress and many will require hospitalization during this time. ? The psychological aspects of social withdrawal, isolation and depression of having cancer, together with the added burden of chemotherapy are real and not exaggerated. ? Some men are much older than my husband and would poorly tolerate chemotherapy. Society may consider them elderly but they could still benefit and thrive with abiraterone. ? Abiraterone as a drug able to be prescribed prior to chemotherapy gives clinicians a real choice to work in the best interests of their patient. ? Abiraterone can delay the use of chemotherapy and may in some cases allow chemotherapy to be avoided altogether. ? Abiraterone is now the 2nd most requested drug on the cancer drugs fund and it is now part of best practice."
Date	04-06-2014

Name	[redacted]

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am not convinced that there is sufficient definitive clinical evidence to conclude that use of arbiraterone before chemotherapy will not have a potential benefit for men like me with advanced prostate cancer
Date	03/06/2014

Name	[redacted]
Role	Public
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	I do not believe arbitrone shpuld only be given after chemotherapy. Arbitrone can delay the need for chemotherapy

recommendations)	and in some cases chemotherapy is not needed. Being able to take a tablet rather than chemotherapy which can be very gruelling and effect you physically and mentally as it is draining, a tablet makes it easier, less uncomfortable, less gruelling. Another important reason is because you can go about things as normal as there arent as many side effects as you get with chemotherapy. Beong able to live a normal, full and active life is vital to those fighting prostate cancer. Please do not wait until men have had to endure something that could possibly have many physical side effects before giving them arbitrone. Please make arbitrone available before chemotherapy and allow these men to live a fuller life in the process.
Date	03/06/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	Any consideration of cost effectiveness should take into account the impact on individuals. - I am currently being treated with Hormone Therapy for Prostate Cancer with extensive bony secondaries in my hips and spine. I have no reason to suppose that this will cease to be effective in the immediate future, but I am concerned about what will happen when it does, and what will happen to other people whose Hormone treatment ceases to work. For myself, if I had to go onto a treatment with debilitating side effects, it might mean that I would need care from my partner who would no longer be able to work (or it might affect his ability to work due to stress - he has already had two longish periods away from work due to the worry and stress caused by my diagnosis) and this could reduce our modest income further which might lead us to being unable to pay our bills, or at least create additional costs to the benefits system.

Name	[redacted]
Comments on individual sections of the ACD:	
Section 8 (Proposed date of review of guidance)	"Please consider the patients and the effects it has on their family, my Dad has prostrate Cancer which at the minute is contained but if he was to need these drugs we would be devastated if he wasn't allowed them because of the price, thanks. Dawn Barber (concerned Daughter)"
Date	03/06/2014

Name	[redacted]
Role	Patient

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	- Abiraterone pre-chemotherapy was approved for use of the Cancer Drugs Fund in January 2013. It has proved popular with clinicians and is now part of current clinical practice. Abiraterone before chemotherapy is now the 2nd most requested drug on the Can
Date	01/06/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am still working full time under the use of this treatment, so very effective in keeping me in the tax area and still a proven benefit to the community.
Section 2 (The technology)	I am taking this treament for more than 15 months, not having had Chemotherpahy. Funded from Cancer fund, only major problem is hypertension.
Date	30/05/2014

Name	[redacted]
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	I cannot understand a lot of the technical detail so difficult to comment. I just know that this drug is a real breakthrough in the treatment on castrate resistant PCa and should be given to any man that could potentially benefit.
Section 4 (Consideration of the evidence)	All the people who have used this on the trial are not necessarily representative of the large numbers of men who need this drug, so the conclusions are not valid.
Date	30/05/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Having read and been involved with a good friend with prostate cancer, I feel it is so important to continue with this drug before chemotherapy has started.As already known, it is the 2nd most common cancer drug, and as such must be allowed to be prescribed
Date	28/05/2014

Name	[redacted]
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Very disappointed with this decision. Making abiraterone available to men who haven't had chemotherapy could allow thousands of men in England and Wales to enjoy the reduced

	side effects and improved quality of life that this important drug can offer earlier on in their treatment.
Date	22/05/2014

Name	[redacted]
Role	Public
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I lost my grandad through cancer, and my father has recently had his prostate removed, it seems to be very common in males, it would be nice to give men the extra time to spend with there family
Date	22/05/2014

Name	[redacted]
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	"Abiraterone pre-chemotherapy was approved for use of the Cancer Drugs Fund in January 2013. It has proved popular with clinicians and is now part of current clinical practice. Abiraterone before chemotherapy is now the 2nd most requested drug requested on the Cancer Drugs Fund. ‐ Prescribing abiraterone pre chemotherapy enables men to delay and in some cases avoid chemotherapy. This means being able to take a tablet at home, rather than travel into hospital for a treatment with significant side effects. ‐ This is a vital drug which should be available to all men on the NHS. If you have received treatment with either abiraterone or chemotherapy, then please do share your experiences with NICE. It?s incredibly important that they hear from people who are directly affected by this decision or concerned about it."
Date	21/05/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Abiraterone pre-chemotherapy was approved for use of the Cancer Drugs □
Date	21/05/2014

Name	[redacted]
Role	Carer
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	"My lovely husband who was 80 last November, fit and healthy all his life, might still be with us for a bit longer if the Wales NHS had given him Abiraterone first instead of chemotherapy.

recommendations)	Absolutely devastated, it's disgusting that they didn't! Please make it available in Wales as well as England."
Date	16/05/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have advanced metastatic prostate cancer and have been on Arbiraterone Acetate and Prednisalone since Jan 2014. My PSA has reduced to 0.5 and scan show that my cancer has shrunk. I continue to work full time and pay my National Insurance and 40% tax every month. How many more are there like me being able to continuing to make a valuable contribution to society ?
Date	14/05/2014

Name	[redacted]
Role	Public
Comments on individual sections of the ACD:	
Date	14/05/2014

Name	[redacted]
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	It seems to me that if the drug can prolong just one mans life, then the cost should not be a factor. This drug should be widely available to all patients that require it. Cost should not be a factor in someone's health and future quality of life.
Date	14/05/2014

Name	[redacted]
Role	Patient
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	"- Abiraterone pre-chemotherapy was approved for use of the Cancer Drugs Fund in January 2013. It has proved popular with clinicians and is now part of current clinical practice. Abiraterone before chemotherapy is now the 2nd most requested drug requested "
Date	14/05/2014