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

Name	[redacted]
Role	Public
Other role	
Location	US
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	How can you put a price on someone's life?
Section 2 (The technology)	How can you put a price on someone's life..
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/9/2014 7:37:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	Could save life's
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Should be used
Section 2 (The technology)	The technology could help to save lifes
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/8/2014 8:38:00 PM

Name	[redacted]
Role	Public
Other role	
Location	US
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Information provided within this guidance does not illustrate why it would be the committee's decision to not recommend the use of Trastuzumab emtansine to treat adults with human epidermal growth factor receptor 2 (HER2) positive. Â In fact, there is more evidence presented here as to why it should be recommended for use. Â For example: 1. Trastuzumab emtansine is both an effective treatment and also well tolerated, with fewer side effects than some of the other options. 2. Trastuzumab emtansine is a novel antibody-drug conjugate combining the HER2-targeted antitumor activity of trastuzumab with a cytotoxic agent. 3. Trastuzumab emtansine prolonged survival, with less toxicity than lapatinib. 4. Capecitabine and trastuzumab emtansine have been shown to have a satisfactory adverse-event profile in EMILIA. Â 4. Most importantly, patients value the availability of more treatment options and trastuzumab emtansine would be welcomed by patients and their families The fact that the committee's rationale for not recommending the use of trastuzumab emtansine is due to it not representing a cost effective use of NHS resources demonstrates poor judgement by the committee.
Section 2 (The technology)	This is a continuation of comment above. Â Cost effectiveness of drugs should not keep lifesaving medicine out of the hands of the public. Â The message NICE is sending is that death is more cost effective than life and that human life is only deemed valuable when the NHS can administer cheap medicine. Â Please reconsider your decision! Â Not recommending the use of the drug will cost human lives. Â Hopefully one day it won?t be yours or someone you love.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	

Date	5/8/2014 3:26:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	this drug is a breakthrough for patients who are running out of options for treatment. It is so important for the patient, the family (a lot of these patients have quite young children and the effect on them of losing a mother so soon in their lives is devastating especially knowing that a successful treatment is available but being denied due to cost).
Section 2 (The technology)	Although it is a costly drug,but in comparison to other costs which will probably be encountered for caring for motherless children and husbands who cannot work because they need to care for their family it pales into insignificance. Most importantly there is extension to someone's life and to their quality of life. Nothing should be disregarded.
Section 3 (The manufacturer's submission)	Please give them a chance
Section 4 (Consideration of the evidence)	Please reconsider and approve this drug. those patients who need it really do need your help.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/8/2014 11:57:00 AM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If there is any chance of helping cancer sufferers, any glimmer of hope, you must provide this. Â You cannot make that choice for someone - there are so many children who need their mothers as long as is absolutely possible. Â You have a moral obligation to give every opportunities to cancer patients. Â How can you not?
Section 2 (The technology)	There should be a better way of funding this, and profit margins limited, to enable this to be accessed by as many as possible. Â What price is life? Â Tell the children who face losing their mothers - look them in the eye and tell them you won't help because of money.
Section 3 (The manufacturer's submission)	You must provide every and any hope possible. Â How can you not?
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	Unless you are 100% certain there is no benefit to this drug then you must provide.
Section 6 (Proposed recommendations for further research)	Please keep researching, developing and making readily available any drug that can help.
Section 7 (Related NICE guidance)	Plead support this drug
Section 8 (Proposed date of review of guidance)	Think if it was your family. Â Please support this drug
Date	5/7/2014 11:22:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	How can you put a price on someone's life Â and deny them treatment to give them extra time that's precious to them and their families. A lot of people who do and don't suffer spend a lot of time raising money for research and now they can't even benefit from it!? So wrong
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This should be made available to anyone that need it regardless of cost!
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 11:01:00 PM

Name	[redacted]
Role	Public
Other role	Fitness instructor
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Section 9 Sources of evidence considered by the Committee	I believe this drug should be available. Monetary value cannot be placed on lives
Date	5/7/2014 9:46:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Don't put a monetary value on th elives of many women who need this drug.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 9:26:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	How can we allow pharmaceutical companies to put such a high price on drugs? Â How can we allow these companies to play God and decide who can afford to live, and who will die?Â We are dealing with people's LIVES. Real people!!! These are our mothers wives, friends, neighbours. Â They are not distant, imaginary people. They are REAL. Let's help them in their battle with this disease.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 9:16:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Section 9 (Sources of evidence considered by the Committee)	The 6 month survival time is misleading!!! This drug has completely reversed disease in some people and has made the disease stable in many more. I want to know WHO is going to tell my two young children when I become resistant to Herceptin and die, that there was a drug to help mummy live longer, but was considered too expensive!! Please reply to carlita_3@hotmail.com at your earliest convenience.
Date	5/7/2014 8:22:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	As the technology is available it should be made available.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 8:00:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	I am a volunteer for Breakthrough Breast Cancer which is campaigning against your decision not to make this drug routinely available.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I can understand this decision as it seems to me that the producers of this drug have priced it very highly. Â I would support any efforts to put pressure on the drug companies to reduce their profiteering from cancer drugs.
Section 2 (The technology)	I am not qualified nor do I have sufficient knowledge to make any comment on the technology.
Section 3 (The manufacturer's submission)	The manufacturer should revisit its profit margins and provide this drug at a cost the NHS can afford.
Section 4 (Consideration of the evidence)	I would only repeat my comments on profit margins etc. above.
Section 5 (Implementation)	unable to comment on this section
Section 6 (Proposed recommendations for further research)	unable to comment on this section
Section 7 (Related NICE guidance)	It would be good if this could be reviewed in line with the ending of the Cancer Drugs Fund in 2016. What will be in place then?
Section 8 (Proposed date of review of guidance)	I do not know any of the members, representatives or project team so can't comment.
Date	5/7/2014 4:52:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I find this recommendation very disappointing as I am a secondary breast cancer patient, currently being treated with trastuzumab. My consultant is looking to T-DM1 as a second line treatment once my current treatment stops working. This recommendation would not allow this to happen on the NHS. By the time I need it, the Cancer Drugs Fund may have finished, leaving me few options for treatment.
Section 2 (The technology)	I agree that the cost of this treatment is high. The drugs company should be challenged where the price is concerned. However, the cost of the drug should be weighed against the amount and quality of extra life it affords to the patient. Side effects are important here. Compared to untargetted chemo treatments, the side effects of T-DM1 are likely to be minimal. Just as transtuzumab delivers bearable side effects compared to chemotherapy.
Section 3 (The manufacturer's submission)	As a lay-person/patient I do not feel qualified to comment on this part of the report.
Section 4 (Consideration of the evidence)	It is really hard for a patient to understand all these conclusions. All I can say is that if patients and clinicians had not campaigned more than ten years ago for transtuzumab (or herceptin as it's more commonly known), then I would not be alive today! It was considered to be a revolutionary new treatment at the time, but too expensive to be cost effective. The cost must have come down or it wouldn't be so widely used today. It is now used to treat primary as well as secondary breast cancer. Who is to say that T-DM1 will not go on to do the same. It too is a revolutionary new treatment and provides hope for those of us whose situation is more than bleak! It should not be rejected on grounds of cost. The manufacturers should be forced to lower their price and not hold the country to ransom!
Section 5 (Implementation)	No comment.
Section 6 (Proposed recommendations for further research)	No comment.
Section 7 (Related NICE guidance)	I hope the comments of those like me whose lives are in NICE's hands will be taken into account in August.
Section 8 (Proposed date of review of guidance)	Are any of these people secondary breast cancer patients?
Section 9 (Sources of evidence considered by the Committee)	I am glad to see charities such as Breakthrough represented in this group. I have been raising money for their research for nearly 15years, so from that point of view it is depressing when a drug produced via outstanding research cannot be used on grounds of cost.
Date	5/7/2014 3:22:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 3:22:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This is totally unfair. What cost to the NHS if a liver/lung transplant patient reoffends by excessive alcohol intake or heavy smoking?
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	have NICE considered the cost effectiveness of misdiagnosis of breast cancer- I was twice misdiagnosed and now cost the NHS more through GP lack of training in recognising breast cancer and metastatic symptoms
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	This review date is excessively too late We need a review August 2014. I have terminal cancer and face uncertain life span- most breast cancer sufferers with advanced cancer have valuable social and emotional if not financial worth in their lives- how can such short-sightedness be accepted?
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 3:09:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	Nothing that I know of!
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This documentation does not take the experience of Kim Mawby into consideration-she has had a very positive experience of this drug.
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	5/7/2014 11:46:00 AM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I agree that is fair and sensible
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	The committee should consider whether the ICER level is realistic. Â I have been heavily treated and I am on Kadlyca and it has changed my life. Â The committee should consider why other countries in Europe and the FDA have approved this drug. Â In the long term we will end of getting it just like the committee got it wrong with Herceptin, Â If these drugs were given earlier it would save money in the long term.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	4/29/2014 2:14:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	After wading through the endless evidence given I am still not Â convinced that NICE have made the correct decision. NICE find it difficult to think out of the box and see the real people that are living for much longer than 6 months on this treatment. The latest lady I read information on has been taking for the past 4 years and doing well. NICE need to trust the doctors to put their patients on the correct treatment for them and in some cases it could be trastuzumab emtansine. We are a rich country that is fulling further and further behind medical advances which will surely in the near future see us as an under developed third world country. For once NICE look to the future and trust the NHS to do their job.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	I have and do receive the above PTD treatment. A year down the line I am well and have clear scans which is showing the treatment is doing its job. This combination may give me many many years as Herceptin has given many others ladies in my situation. This is a new age of drugs working together to improve survival and at some point cure its patients.We need to advance our treatments not stand back and watch.
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	4/28/2014 5:49:00 PM

Name	[redacted]
Role	Public
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I strongly support the recommendation that people currently receiving treatment continue to receive it due to the trauma that withdrawing a treatment that has commenced could cause.
Section 2 (The technology)	I comment that an artificial market means that prices are inflated.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	I comment that an earlier review prior to the expiry of the Cancer Drugs Fund would be beneficial to prevent a potential gap in funding.
Section 8 (Proposed date of review of guidance)	
Date	4/24/2014 9:01:00 PM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	As a 24 year old female diagnosed with advanced her-2+ breast cancer. I understand the value of these drugs. In 2013; I had docetaxel, radiotherapy and continue to have herceptin. Since March this year i have returned to full time work and contribute to taxes and national insurance. I speak to a number of people with Â advanced breast cancer Â and other advanced cancer who all work part or full time or want to go to work. When you think of the side effects and quality of life T-DM1 brings people can potentially can work and contribute to society. I feel that this is never considered and Â believe that support should be given for cancer patients to return to work. I also believe that cuts and removal of other needed care services could be made to fund much need drugs like this. For someone like myself being so young it is not fair my life should be cut even shorter by money. When i want to live life work, pay taxes and spend it to help the economy grow.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	
Section 8 (Proposed date of review of guidance)	
Date	4/24/2014 9:54:00 AM

Name	[redacted]
Role	Patient
Other role	
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	
Section 2 (The technology)	My clinician thinks this is the best drug option for me and this decision will prevent me from even trying it. Possibly condemning me to death and my child to the loss of his mother. Costs associated with loss of a productive member of society should be taken into account as well as costs like that of caring for my elderly mother that the state will end up paying for.
Section 3 (The manufacturer's submission)	
Section 4 (Consideration of the evidence)	Those patients with compromised immune systems like RA sufferers have not been Considered.This drug would appear to be more suitable for them than just trastuzumab during earlier treatment.
Section 5 (Implementation)	
Section 6 (Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	The review should take place in 2016 when the drug stops being available via the cancer care fund. If the price reduces between now and 2016 to an acceptable cost a review should be undertaken at that time too.
Section 8 (Proposed date of review of guidance)	
Date	4/23/2014 8:13:00 PM