Patient/carer organisation statement template

Thank you for agreeing to give us your views on the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on the technology, which is not typically available from the published literature.

To help you give your views, we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. Please do not exceed the 8-page limit.

About you

Your name: Barbara Moss

Name of your organisation:

_____

Are you (tick all that apply):

- **a patient with the condition for which NICE is considering this technology?** √
- a carer of a patient with the condition for which NICE is considering this technology?
- an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology? If so, give your position in the organisation where appropriate (e.g. policy officer, trustee, member, etc)
- other? (please specify)

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. Advantages
(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

Adding Bevacizumab to my treatment for bowel cancer enabled what was a previously unresectable tumour in my liver to become resectable, therefore transforming what was a terminal disease into one that was possibly curative.

In my case, not only did the Bevacizumab shrink the tumour dramatically, but it also cleared the portal vein in the liver, which it was touching in order for resection to be done. I believe the drug would have similar positive effects on other patients.

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

Bevacizumab stopped the disease in its tracks. It blocked what would otherwise have been a rapidly progressive growth of the disease in my liver and stabilised my condition.

There was significant improvement in the way I felt as a result of receiving Bevacizumab: the weight and pain in my liver reduced with the shrinkage of the tumour. Before taking the drug, I was extremely tired, but after I started taking it I felt more active, my level of disability was reduced and I was able to get about more, thus improving the quality of my life both socially and in helping around the home. This, of course, had a direct impact on those closest to me, offering a light in an otherwise bleak world.

It should be noted that before Bevacizumab was added to my chemotherapy, my CEA level was only reducing at a slow rate. The addition of Bevacizumab brought my CEA levels back to normal and there was a dramatic effect after only two treatments of the four prescribed, along with shrinkage of the tumour as shown in a CAT scan at this time.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. Disadvantages
Please list any problems with or concerns you have about the technology. Disadvantages might include:
- aspects of the condition that the technology cannot help with or might make worse.
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel needed to access the technology, or the cost of paying a carer).

From my own experience, there was no difficulty, complication or negative effect when Bevacizumab was added to my regime. On the contrary, it had a positive effect on me and on my whole family.

Having previously had Oxaliplatin and then Irinotecan with 5FU and then with Capecitabine, I was well aware of the side effects of these drugs, which were extensive. The addition of Bevacizumab did not add any side effects; instead it improved my general wellbeing and also gave me hope.

I had been given a list of all possible side effects by my clinical team, but experienced none of them. My blood pressure is already high and I have regular treatment for this. Bevacizumab caused me no further complications.

With an initial prognosis of 3 to 5 months to live, there are a number of things one is prepared to endure, as I did with the previous chemotherapy regimes. Bevacizumab did not cause any problems when added to my drug regimen.

There was also no added cost of travel, as the drug was administered in the same place as my chemotherapy. However, having to pay for the drug as I did and having to fight bureaucracy when fighting a major disease was totally disabilitating.

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

In 2007, most patients were not aware or even informed about monoclonal antibodies. I was involved in my treatment from the start and researched these new drugs, Bevacizumab and Cetuximab, myself. When I discussed these with my oncologist, he firmly believed that I could benefit from this technology and I did feel the benefit immediately. In recent months, the profile of this drug has increased with much media coverage and since I was treated I have met many people who have had Bevacizumab (and Cetuximab) with similarly positive results.

4. Are there any groups of patients who might benefit more from the technology than others? Are there any groups of patients who might benefit less from the technology than others?

It is vital for every patient to be able to trust the expertise of their clinician to prescribe the best drugs for them on a personal basis and for them to be able to do so. This trust would be lost if conditions could not allow this, e.g. by this drug not being approved by NICE, and if financial accountants at PCTs continued to be allowed to overrule the recommendations of clinical experts.

Comparing the technology with alternative available treatments or technologies

NICE is interested in your views on how the technology compares with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

I can relate to having had conventional chemotherapy and being told that resection was still not possible. I was then advised by a top surgeon in England to 'go and ask for Avastin'. I was aware of Bevacizumab and Cetuximab and how they worked, because I researched all the drugs that were available at that time. I realise that I was one of the first patients in this country to benefit from these new drugs but that other patients were not told about them.

I also often discussed my treatment as compared with conventional chemotherapy. Unfortunately, I had to pay for it but what price do you place on your life?

(ii) If you think that the new technology has any advantages for patients over other current standard practice, please describe them. Advantages might include:
- improvement in the condition overall
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
- side effects (please describe nature and number of problems, frequency, duration, severity etc.)

As I do not consider my experience to be unique, I am certain that this new technology would have benefits to other patients if their clinicians were able to use their expertise in deciding what is suitable for each patient.

For me, using Bevacizumab speeded up the whole process that led to resection of both my tumours in the liver and ascending colon. In these circumstances, there is no time to waste. I have heard from other patients, both personally and in reading their stories in the media, how they have benefitted from Bevacizumab as well as I did.

(iii) If you think that the new technology has any disadvantages for patients compared with current standard practice, please describe them. Disadvantages might include:

- worsening of the condition overall
- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

There was no disadvantage whatsoever, nor any difficulty in the administration of Bevacizumab.

Research evidence on patient or carer views of the technology

If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

When I was prescribed Bevacizumab, I was not aware of any other patients taking this drug. Since then, I have met others who have all told me about its benefits, particularly that of slowing down the rapid progression of their cancer. Given the opportunity, I am certain that other patients would welcome the possibility of being given access to this drug.

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

I was made aware of possible side effects but did not suffer any and would hope that other patients would be given this information.

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

Please refer to 4 above.

Availability of this key technology to patients in the NHS

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

I have gone from being terminally ill to being free from the disease, which is in a large part due to receiving Bevacizumab. However, while I benefitted from being treated with Bevacizumab, I had to find the resources to pay for it and struggled over a prolonged period to get some of my NHS costs refunded.

No patient should have to undergo sitting around a table with a dozen other people on a panel in order to get the treatment recommended by all the medical experts they are being treated under. Neither should any patient with possible limited time left in life have to spent hours upon hours filling in administrative forms.

It has been proven that Bevacizumab prolongs life and quality of life at the least, helping people to come to terms with their situation in this extra time. Let it be that NICE now puts right the injustice and needless fear and stress that other people, like myself, have had to go through as a result of this.

What implications would it have for patients and/or carers if the technology was not made available to patients on the NHS?

It would mean that more patients would have to go through similar difficulties as described above, causing financial worries on top of everything else. It would mean that choice is restricted. People are now well aware of monoclonal antibodies and their possible benefits. How can anyone trust their clinician if they are not even told about the best possible treatment that is now available or are not able to get it?

Are there groups of patients that have difficulties using the technology?

Each patient will have a differing circumstance and needs the advice of their clinician.

Other Issues

Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.

I know I am not unique in my response to Bevacizumab. Cetuximab has recently been approved for first line treatment by NICE, but only a relatively small proportion of patients can benefit from it. What about the others with bowel cancer? It is totally unfair to exclude from the start the chance for a large proportion of people to have the benefit of new technology using monoclonal antibodies. I'm living proof of someone who has benefitted from Bevacizumab; who has gone from being considered "terminal" to being cancer free. But I had to pay for the drug myself; fight ignorance and bureaucracy to get it; and fight to be refunded. I hope that NICE approves the drug, so the next generation of patients has the chance to benefit from the drug without all of these inequities.