

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:

Hannah Millington

Name of your organisation:

Nominated by Bone Cancer Research Trust

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology?
* I am a former osteosarcoma patient
- 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.

Survival rates for osteosarcoma are relatively low when compared to other more common cancers. The arrival of a new therapeutic advance in osteosarcoma that would improve survival rates is a hugely important development for patients and their families.

(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.

The most significant benefit to patients is that this technology improves the chances of survival, meaning that patients can go on to have a full life expectancy as osteosarcoma affects mainly children, teenagers and young adults.

This would mean that there is more opportunity for these survivors to realise their potential and make a positive contribution to society.

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).

I am unaware of any disadvantages and have no concerns about this technology. I have been told that the side effects of mifamurtide are minimal and can be compared to flu-like symptoms. My understanding is that it can be easily tolerated by most patients and side effects can be easily treated with paracetamol. The side effects of mifamurtide appear to be minimal when compared to the side effects of aggressive and gruelling chemotherapy.

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

Not that I am aware.

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?

Comparing the technology with alternative available treatments or technologies

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

(i) Please list any current standard practice (alternatives if any) used in the UK.
Combination treatment with chemotherapy and surgery.

(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.)

Improving survival-there have been no significant advances in systemic chemotherapy or in survival rates for osteosarcoma patients over the past 20 years. Survival benefits of mifamurtide have been clearly demonstrated.

(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).

I am not aware of any disadvantages, I believe the fact that mifamurtide offers an improved chance of survival and a chance to lead a full life means that patients would want this treatment. Although it would extend the length of treatment beyond the end of chemotherapy it can be given as an outpatient. I understand that mifamurtide is relatively easy to take and has mild side effects that are much less gruelling than chemotherapy.

Appendix I – Patient/carer organisation statement template

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.

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

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.

Availability of this 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?

Mifamurtide offers a better chance of survival; that is the greatest difference a technology can make to patients and their families. Having mifamurtide is not a trivial benefit it is a significant benefit.

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

Patients would not be able to access the first treatment in 20 years that has shown improved chances of survival.

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

Other Issues

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

Osteosarcoma is a rare cancer that affects predominantly children, teenagers and young adults. The average age of someone diagnosed with this disease is 15. Mifamurtide improves survival rates, this means that if patients benefit from the treatment they will go on to live a normal/near normal life span. Osteosarcoma is so contrary to the usual way of life due to the age of people that it affects, however, patients can be effectively treated and go on to lead full and active lives. As a former patient I have a good quality of life and contribute as an equal member of society, A treatment that offers survival benefits for a cancer that hasn't seen improved survival

Appendix I – Patient/carer organisation statement template

rates in 20 years is something of immense significance and would improve outcomes for children and young people diagnosed with osteosarcoma and should be made available to patients as a matter of urgency.