

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: Sally Hurst – patient expert

Name of your organisation: Nominated by Bone Cancer Research Trust

Other Issues

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

Personal Statement to the NICE Appraisal Committee

Sally Hurst

Osteosarcoma patient and trustee of the Bone Cancer Research Trust

I confirm that I agree with the statement submitted by the Bone Cancer Research Trust, but am submitting my personal statement in addition

My background/personal experience of the disease

I was diagnosed with osteosarcoma in 2005, when I was 26 years old. I was shocked to be told that not only did I have a very rare cancer; my chance of survival was only 55%. This was psychologically distressing and made coping with what is an extremely gruelling chemotherapy regime very difficult.

Unfortunately my cancer did not respond well to the standard chemotherapy treatment, so in July 2005 I took the very difficult decision to have my right leg amputated above the knee, rather than having the limb-saving operation that is more commonly carried out. As a patient, the most important thing to me was surviving. Amputation gave me a greater chance of surviving so I was prepared to accept a disability. I now use an artificial limb.

I finished nine months of chemotherapy in December 2005 and have remained disease-free to date, although still have regular check-ups. I am aware that my cancer could come back and I can only hope that I am part of the 55% of osteosarcoma patients who survive long-term.

Survival has meant that I have been able to return to work full-time, have got married and have had a baby. I have also become a trustee of the Bone Cancer Research Trust.

Comments on Mifamurtide

- Survival rates for osteosarcoma are relatively low, when compared to other more common cancers, and there have been no significant advances in systemic chemotherapy or in survival rates over the past

20 years. Therefore the arrival of a new therapeutic advance in osteosarcoma, which would improve survival rates, is an exciting development for patients and their families.

- Osteosarcoma mainly affects young people, and increased numbers of young people surviving the disease would mean more opportunity for these survivors to realise their potential as contributors to society, in both work and family life.
- Mifamurtide would extend the length of treatment beyond the end of chemotherapy. The current chemotherapy regime lasts for approximately nine months, and I might have been reluctant to prolong my stay in hospital for further treatment. But significantly, Mifamurtide can be given as an outpatient, with infusions lasting only an hour twice-weekly or once-weekly. The prospect of once or twice-weekly visits to the hospital once chemotherapy had finished would not have worried me, especially given the improved survival chances of taking the drug.
- I was interested to find out about possible side effects of Mifamurtide, especially since the current chemotherapy treatment is physically gruelling. Had the short-term side effects of Mifamurtide been severe, I might not have wanted to endure it in addition to chemotherapy. However, the flu-like symptoms reported in the clinical study, which are easily treated with paracetamol, appear minimal when compared to the chemotherapy side effects.
- I note the findings relating to hearing loss, but on balance, I believe the improved survival chances of taking the drug outweigh the risk to hearing - which is also one of the numerous side effects pointed out to patients as a risk of taking the chemotherapy drug cisplatin.
- I am concerned about the suggestion for further clinical studies to be undertaken before Mifamurtide is recommended for use on the NHS: Osteosarcoma is a rare disease; there are fewer than 200 patients a year in the UK, so to try and repeat a clinical study of this size would take years. **Given that the survival benefits have already been demonstrated, I believe this drug should be made available on the NHS without further delay.**

Sally Hurst

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