NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Talimogene laherparepvec for treating metastatic melanoma [ID508]

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, including health-related quality of life)
- preferences for different treatments and how they are given
- expectations about the risks and benefits of the treatment.

We have already asked your nominating organisation to provide an organisation's view. We are asking you to give your views as an individual whether you are:

- a patient
- a carer (who may be voicing views for a patient who is unable to) or
- somebody who works or volunteers for a patient organisation.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The response area will expand as you type. The length of your response should not normally exceed 10 pages.

1. *About you*

Your name:
Name of your nominating organisation: Melanoma UK
Do you know if your nominating organisation has submitted a statement?

☐ **Yes** ☐

Do you wish to agree with your nominating organisation's statement?

☐ Yes ☐

(We would encourage you to complete this form even if you agree with your nominating organisation's statement.)

Are you:

- a patient with the condition?

☐ ☐ **No**

- a carer of a patient with the condition?

☐ ☐ **No**

- a patient organisation employee or volunteer?
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☐ **Yes** ☐

Do you have experience of the treatment being appraised?

☐ ☐ **No**

If you wrote the organisation submission and do not have anything to add, tick here ☒ (If you tick this box, the rest of this form will be deleted after submission.)

2. *Living with the condition*

What is your experience of living with the condition as a patient or carer?

Speaking regularly with advanced melanoma patients there is no doubt that this is a very serious and debilitating disease. Advanced Melanoma is a brutal disease and a patient living with the disease without treatment can expect to survive between 3-9 months without treatment. The disease disproportionally affects young people and in an advanced stage, this can mean a young patient is looking at a very limited life expectancy and all the trauma that that brings.

3. *Current practice in treating the condition*

Which treatment outcomes are important to you? (That is, what would you like treatment to achieve?) Which of these are most important? If possible, please explain why.

Treatment in advanced melanoma has always been a complicated area of medicine. Up until the last few years, advanced melanoma was notoriously difficult to treat. Patients and clinicians had limited treatment options. The treatment being appraised today has been seen as a step change in the treatment of advanced patients. Patients have reported reduction in tumours and minimal side effects. The side effects of some treatments are debilitating and this is a very important issue for patients and carers. This treatment is of particular interest to patient who are presenting with tumours that are visible to the outside world. We have had reports of patients who are desperate to be considered for this treatment.

What is your experience of currently available NHS care and of specific treatments? How acceptable are these treatments – which did you prefer and why?

As a patient advocacy group we are aware of other treatments in advanced melanoma. Not all of them are appropriate or suitable for all patients and each treatment has its own advantages and disadvantages. Given that we only have anecdotal evidence from patients as to the efficacy of these treatments, it is really for the patient expert to advise on acceptability.

4. What do you consider to be the advantages of the treatment being appraised?

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

Please list the benefits that you expect to gain from using the treatment being appraised.

Improved prospect of quality, long term survival. Evidence of improved patient outcomes and experience to Melanoma UK's knowledge.

Patients have been made aware of instances of better progression free survival which is being seen compared to other treatments and standard of care. Patients understand that there may be a reasonable side effect profile which is important to them.
Targets an area of high unmet need. Melanoma is on the increase in the UK and leading clinicians have made it clear that there is a desire to be able to offer as many alternative treatments as possible as early as possible in the treatment pathway. This is not just limited to clinicians – patients and carers have a strong appetite to have access to as many treatments as possible.

Please explain any advantages that you think this treatment has over other NHS treatments in England.

Dealt with above

If you know of any differences in opinion between you and other patients or carers about the benefits of the treatment being appraised, please tell us about them.

5. What do you consider to be the disadvantages of the treatment being appraised?

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)
- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)
- any other issues not listed above

There will always be the risk of adverse side effects or the treatment not being suitable for the treatment, but just as with other melanoma treatments, patients are anxious for this to be another option.

Please list any concerns you have about current NHS treatments in England.

Please list any concerns you have about the treatment being appraised.

If you know of any differences in opinion between you and other patients or carers about the disadvantages of the treatment being appraised, please tell us about them.

6. Patient population

Do you think some patients might benefit more from the treatment than others? If so, please describe them and explain why.

Do you think some patients might benefit less from the treatment than others? If so, please describe them and explain why.

7. Research evidence on patient or carer views of the treatment

Are you familiar with the published research literature for the treatment?

☐ Yes ☐ **No**

If you answered 'no', please skip the rest of section 7 and move on to section 8.

Please comment on whether your experience of using the treatment as part of routine NHS care reflects the experience of patients in the clinical trials.

Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?

If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?

Are you aware of any relevant research on patient or carer views of the condition or existing treatments?

☐ Yes ☐ No

If yes, please provide references to the relevant studies.

8. *Equality*

NICE is committed to promoting equality of opportunity and eliminating discrimination. Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, who they are and why.

9. *Other issues*

Do you consider the treatment to be innovative?

☐ **Yes** ☐ No

If yes, please explain what makes it significantly different from other treatments for the condition.

There is the suggestion that this treatment can have a dual effect - killing cancer cells directly and harnessing the immune system against them.

Is there anything else that you would like the Appraisal Committee to consider?

We say similar things every time we appear before the committee, but to reiterate : until very recently, advanced melanoma patients have had little hope of long term survival. This is another new treatment which is showing such promise and patients are anxious that there is another treatment made available to them. Melanoma is a brutal disease and patients are desperate for any treatments that might help them to be able to function at a proper level.,

10. *Key messages*

In no more than 5 bullet points, please summarise the key messages of your submission.

- Meets the need of advanced melanoma patients
- Reasonable side effect profile
  - Another option for patients and clinicians
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