NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Ipilimumab for previously treated unresectable malignant melanoma

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: [redacted]

Name of your organisation: [redacted]

Are you (tick all that apply):

- **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)**

  Chief Executive

- **a carer of a patient with the condition for which NICE is considering this technology?**

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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.

Ipilimumab is welcome news for patients who have had few treatment options until now.

Ipilimumab is the first treatment to show a survival benefit to patients since the 1970's – until now there have been 30 years without any real treatment advantages

The treatment is palliative but has been shown to prolong life in some patients

Average life expectancy if diagnosed with advanced melanoma is around 6-9 months – in trials 25% of patients on ipilimumab are still alive at 2yrs.

The current standard of treatment (Dacarbazine) is relatively ineffective – advanced melanoma is a very resistant and often aggressive cancer

Dacarbazine is a typical 1970s form of chemotherapy with all of the nasty side effects one associates with that whereas the side effects of ipilimumab are largely manageable

Ipilimumab requires just a single treatment sequence over roughly 3 months – not something you have to take every day for as long as you live

(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.

As ipilimumab controls the symptoms of malignant melanoma it inevitably improves the

- ***physical symptoms***
- ***mental health***
- ***quality of life***

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This inevitably has huge benefit on the quality of life and experience of people with and those affected by malignant melanoma.

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).

The advantages far outweigh the disadvantages

Patients consider some of the side effects of ipilimumab to be far less than with current palliative chemotherapy (Dacarbazine) and for the more common side effects - diarrhoea, skin rash and fatigue – relatively easy to manage/control.

Patients will need specific information about the potential for immune side effects and to consider the potential for that to be life threatening.

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

No

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?

This treatment may not be suitable for people who were pre-morbidly immune-compromised.

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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.

Dacarbazine

(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.)

Dacarbazine has significant side effects that greatly reduce the quality of life for people with malignant melanoma. It requires IV infusion in a hospital setting as a course of chemotherapy
whereas
Ipilimumab is a single treatment every 3 months

Currently at this stage of their illness life expectancy is 6-9months but in trials 25% of patients on ipilimumab are still alive at 2yrs.

(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 is a risk of immunosuppression with ipilimumab.

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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.

N/A Ipilimumab is not currently available as part of routine NHS care.

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

N/A Ipilimumab is not currently available as part of 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.

N/A

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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?

It would provide a new treatment that would potentially increase the life expectancy, provide good symptom control and an alternative to aggressive chemotherapy.

At this stage of their illness life expectancy is 6-9months but in trials 25% of patients on ipilimumab are still alive at 2yrs.

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

It would leave people with malignant melanoma without an effective palliative treatment.

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

No

Equality

Are there any issues that require special attention in light of the NICE's duties to have due regard to the need to eliminate unlawful discrimination and promote equality and foster good relations between people with a characteristic protected by the equalities legislation and others?

Other Issues

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

A significant number of people dying with malignant melanoma are under 40 – any treatment that prolongs and improves the quality of their life must be provided as an NHS treatment. In 2008, 110 people aged under 40 died from malignant melanoma