NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Melanoma (previously untreated stage III or IV) - ipilimumab [ID74]

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: N/A

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)

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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 successfully treated stage 4 melanoma.
In terms of disease progression my melanoma had spread to all parts of my body and had not responded to other trearments.
Lesions reduced even after the first cycle.

(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 main advantage of Ipilimumab, in my case, was the long term survival benefit.
I was diagnosed at stage 4 in January 2007, with most areas of my body affected, but now live cancer free 7 years later.
Skin lesions responded immediately to the treatment and reduced significantly within the first two treatment cycles.
Discomfort brought on by the condition was therefore reduced.
I was able to return to a normal working life post treatment when the side effects had subsided.
The treatment is administered as an intravenous infusion into a vein which obviously took place in a hospital setting, but a single course of treatment only took about 90 minutes. Therefore lengthy hospital stays were unnecessary for the administration of the treatment.

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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).

Treatment was only available in a specialist centre. This therefore involved a certain amount of travel. I felt however that this was acceptable given my circumstances with a supportive care network of family and friends.
Side effects were debilitating and slow to overcome. Bodily functions only returned to normal about 6 months post last cycle of treatment.
I suffered inflammation of the bowel and colitis resulting in stomach pains and diarrhoea, also vomiting, and fever, which made day to day life difficult.
These conditions lead to extreme fatigue and physical weakness.

I was unable to work on several occasions whilst undergoing treatment and only fit to return after 6 months after my last treatment, initially on a part time basis.

Vitiligo affected my skin and hair.

However, I was willing to tolerate all of these side effects in light of the overall benefit.

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

I am unaware of any other patients who have undergone similar treatment.

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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?

In my opinion the treatment would need to be considered carefully for pregnant women and possibly diabetics or those undergoing treatment with immunosuppressants.

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.

Chemotherapy (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.)

In my case chemotherapy had little effect on the condition. The size of my lymph nodes in my neck reduced however skin lesions increased in size and number with treatments of Dacarbazine.

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(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).

Side effects are greater with ipilimumab, however this is outweighed by the overall long term survival benefits.

Equality and Diversity

NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- Could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- Could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- Could lead to recommendations that have any adverse impact on people with a particular disability or disabilities

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts

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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.
As a non-clinician I am unaware of any evidence base or research on the subject.

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.

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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?

Standard treatments for stage 3 and 4 melanoma have proved unsatisfactory. Ipilimumab offers hope that a full recovery, such as in my case, can be made. Ipilimumab has been proven to extend life in this stage 4 melanoma patient and therefore should provide hope for future patients diagnosed with metastatic disease. I can now play a full and active role in both employment and family life and continue to contribute to society positively.

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?
Life expectancy and survival rates from melanoma will remain unacceptable.

Are there groups of patients that have difficulties using the technology?
In a hospital setting the treatment could be administered to all patients where intravenous infusions are appropriate.

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