NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

STA Ipilimumab for previously untreated 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: Melanoma UK

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)

About Melanoma UK

Melanoma UK is a patient support and advocacy group, set up in 2007. The group was set up in memory of Jon Herron, a young man from Larne in Northern Ireland who sadly passed away in May 2008. Initially the aim was to fund raise and raise awareness of melanoma.

The group started off as Factor 50 and became Melanoma UK IN 2013. We have gone much further than we could have ever hoped and we are now part of the Government's melanoma task force team and give patient support to as many melanoma patients and families as we possibly can.

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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.

Improved prospect of quality, long-term survival

Evidence of improved patient outcomes and experience, to Melanoma UK's knowledge, based on second line use of Yervoy to date, and strong first line trial data. The primary outcome observed in trials relates to the increased potential for improved quality survival, with secondary outcomes relating to increased time to disease progression and improved health-related quality of life (noted in NICE first line guidance, attached).

The significant number of additional patients that could benefit if Yervoy is recommended for first line treatment, based upon evidence showing that those patients treated earlier with Yervoy will be more likely to receive the full treatment course and therefore experience the full benefit. (Full treatment is 3 mg per kilogram of body weight (mg/kg) administered intravenously over a 90-minute period every 3 weeks, with a total of 4 doses).

A highly innovative advance in treatment

One of the most innovative treatments in recent years.

An effective immuno-therapy, the benefits of which could be significantly enhanced by extending the treatment to patients at an earlier stage in the pathway.

Targets an area of high unmet need

Highlight the rising incidence of melanoma in the UK (British Journal of Oncology, 2011).

Highlight that clinicians have expressed a desire to be able offer Yervoy at an earlier stage of the pathway to patients (a quote from a leading clinician would support this point).

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(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

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 thier family (for example cost of travel needed to access the technology, or the cost of paying a carer)

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

Strong patient appetite for Yervoy as a first line treatment option

Melanoma is a disease that affects the young as well as the old.

Letters from patients and unnamed case studies could support this, if Melanoma UK has received such representations.

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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?

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.

Dacarbazine.

Vemurafenib (only for BRAF V600 mutation-positive patients).

(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 of 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)

Highlight the toxicity issue with dacarbazine and what this means for patient experience and quality of life.

Highlight that Yervoy has been shown to be effective, but less than optimally effective when used as a second line treatment option following dacarbazine and/ or vemurafenib - the additional potential to improve outcomes with Yervoy when given at an earlier stage in the pathway is important.

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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).

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?

This is an opportunity to highlight what extended quality survival means to patients and families, on a physical and an emotional level, citing unnamed case studies if possible.

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

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

Equality
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.

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