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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: Melanoma UK

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)

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 began as Factor 50 and became Melanoma UK in 2013. We have gone much further than we could ever have hoped and provide much needed patient support to as many patients and families as we 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. This was noted in NICE first line guidance.

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 3mg 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 innovate 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. 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 Yervoy at an earlier stage in the treatment pathway. This is not just limited to clinicians – patients and carers also believe there is a strong argument for using Yervoy at an earlier stage.

(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

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- 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.

Patients report that they are being informed of benefits to late stage patients who begin Yervoy and believe that they too would benefit from treatment, but believe that consideration needs to be given to use at an earlier stage. Instead of patients becoming more fragile and in more serious situations, they feel the benefits of earlier use would assist them in the immediate future. For example, mentally – they would not find themselves wondering whether the disease is progressing to a point where they will be exempt from treatment – they feel there is a valid argument for using Yervoy earlier, as opposed to treatments with poor outcomes. This is echoed by families of patients.

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).

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Whilst patients are aware of certain side effects of the treatment, the patients that I have monitored and spoken to, are prepared to acknowledge the side effects and deal with them as and when they arise. The alternatives for most patients are unthinkable. As far as any financial implications are concerned, most patients are willing to undertake treatments at a financial risk – given that should the treatment succeed, they might be in a position to return to full time employment in any event.

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

There is a very strong appetite for Yervoy as a first line treatment option.

Melanoma is a disease that affects the young as well as the elderly. Supporting documentation and statements from patients are available.

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 with existing treatments for this condition in the UK.

	(i) Please list any current standard practice (alternatives if any) used in the UK.
Dacarbazine	

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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 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.)

There is the issue of toxicity with use of dacarbazine – this can mean reduction in quality of life for some patients.

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.

(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).

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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

Research evidence on patient or carer views of the technology

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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.

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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?

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?

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