

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: Mr Richard Jackson

Name of your organisation: N/A

Are you (tick all that apply):

- 1 a patient with the condition for which NICE is considering this technology?
- 2 a carer of a patient with the condition for which NICE is considering this technology?
- 3 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)
- 4 other? (please specify)

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

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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.

Being diagnosed with malignant melanoma in 2006 there was no effective treatment available. My only course of action was to offer myself for trials at a hospital undertaking them. Traditional chemotherapy in the form of Dacarbazine proved ineffective in halting the development or growth of skin lesions and therefore my life expectancy was short. Ipilimumab, stopped the development of new skin lesions and effectively reduced existing sites to the point where no detectable sites remain. Without doubt, ipilimumab has prolonged my life.

(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.

Since completing the treatment in 2008 I have returned to full time work and am able to provide for my young family. Although the spectre of cancer still effects my daily life I am able to live a relatively normal existence making a positive contribution to society, as an Assistant Headteacher of a primary school. I have no remaining physical symptoms of the disease or disability, and my friends and family now contribute not to my care, but to my general wellbeing.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

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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).

I was treated as an outpatient, undergoing blood tests before receiving new doses of ipilimumab. My treatment took place at the Christie Hospital.

The side effects began 7-10 days after my first treatment. I experienced severe diarrhoea, on which Imodium had no effect, and colitis which meant I had little or no control over my bowels. I had weight loss and extreme fatigue, unable to work or contribute to household tasks.

I was susceptible to infection and was hospitalised twice when my condition deteriorated for periods of about five days, until I recovered.

After further courses of treatment I became intolerant of most foods, in particular lactose and gluten, which would only remain in my system for a matter of minutes. My BMI was measured by my GP as 17.5 at this point. An emergency appointment with a dietician helped this recover, through the prescription of a food supplement drink.

I have also suffered whitening to large patches of my skin and body hair.

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

N/A

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?

N/A

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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 existing treatments for this condition in the UK.

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

Traditional 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.)

The chemotherapy had little or no effect on my condition. I did feel that due to a reduction in my immune system, there was an acceleration in the incidence and size of skin lesions post treatment during chemotherapy. It contributed little to my condition overall, which continued to develop. New skin lesions were noticeable on my skin daily and size of existing ones increased. Ipilimumab stopped the development and reduced the size of lesions. Scans showed, after about three cycles, a reduction in measurable lesions of about 60%.

(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

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home)

- side effects (for example nature or number of problems, how often, for how long, how severe).

Both treatments are administered via a drip in hospital, the chemotherapy causing great discomfort. The ipilimumab has greater side effects as described above, however the benefits are considerably higher.

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

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

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

Availability of this technology to patients in the NHS

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What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

Ipilimumab will have a tremendous effect on both patients and patients families if made available. I have benefited greatly from the treatment, returning to a normal family life, having feared the worst. Outcomes for patients with metastatic melanoma are poor, this is the first hope for years that there is a successful treatment for the condition, that will prolong life.

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

Lives will continue to be lost to this disease, leaving families devastated.

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

N/A

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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?

N/A

Other Issues

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