

Patient expert statement

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: **DR JESME BAIRD**

Name of your organisation (if applicable):

THE ROY CASTLE LUNG CANCER FOUNDATION

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) **MEDICAL DIRECTOR**
- other? (please specify)

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.

1. For the overwhelming majority of NSCLC patients, cure is not a treatment option. Median survival is less than 6 months from diagnosis. In this scenario, improving quality of life and small extensions in duration of life are of considerable significance to the individual and their family.

2. This treatment offers the possibility of improvements in survival and quality of life.

3. As active treatment options are so limited in NSCLC and as outcomes remain so poor, the availability of new choices, offer 'hope' for patients

4. Faced with incurable disease, worsening symptoms and a short life expectancy, it is clear that individual sufferers feel cost should not be a factor in deciding treatment options.

The issue of "inverse weighting for duration of life" must be stressed. When considering the cost of treatment, it is not appropriate, for example, to give the same weighting to the final six months of life as to all other six months of life. It is important for this to be part of any numeric equation, which is looking at cost and quality of life. This point is of crucial importance to patients and relatives in this desperate situation

(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.

1. Improvement in symptoms. Patients with advanced non small cell lung cancer are often debilitated with multiple and distressing symptoms. Symptoms such as breathlessness are very difficult to manage clinically. Therapies with anti-tumour activity often provide the best option for symptom relief. The reality, however, is that few options currently exist. Pemetrexed provides such a treatment choice.

2. The potential of improving quality of life brings obvious benefits. These patients, in general, have limited life expectancy. It is of paramount importance, both to them and their families, that they are able to function as fully as is possible.

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 it 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).

As with other anti cancer treatments, Pemetrexed has an associated side effect profile. We are not aware of any specific disadvantages associated with it.

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

Quite obviously, patients with good response to Pemetrexed have better opinions. However with so few options available, even those who do not respond will have "benefited" by receiving an active treatment option.

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?

We have no information on this.

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.

In second line treatment for advanced non small cell lung cancer, intravenous chemotherapy is the standard active treatment. Pemetrexed provides an alternative, with different mode of action and side effect profile.

(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.)

As above, Pemetrexed has a different mode of action and side effect profile from current standard treatment.

(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.

Yes, as far as we can ascertain, it does. The research, however, does not give any indication of the overwhelming "hope" which this desperate group of patients have, in receiving a drug, with potential anti-cancer activity.

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

None have come to our attention.

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.

We are not aware of any specific published 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?

If this technology were not available on the NHS, patients would be denied a treatment option which, for some, would provide benefit in terms of quality and length of survival.

As we have seen with other new anti-cancer agents in this position, those who are se histories, highlighting the length to which patients currently have to go to access Erlotinib, in situations where it is currently not available on the NHS. In two cases, the patients have financially able, will access it in the private health sector The vast majority will not be able to do so.

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

As above, if this were the case, it will only be those who could afford to pay for Pemetrexed, who would be able to access it. Since lung cancer is a disease particularly associated with those in low income groups, those in greatest need will be further disadvantaged.

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

I am unaware of any specific groups.

Other Issues

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

We urge NICE to take account of the patient views expressed above. In short, this product should be approved if the research evidence shows that it can improve, however modestly, the quality of life and/or duration of survival for this patient group or if it offers comparable benefit to other available treatments, but with lower patient toxicity. We believe that Pemetrexed meets these criteria