

Patient/carer organisation statement template

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 FOX

Name of your organisation: 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?

YES - 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)

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.

Of obvious importance, is improved survival and better quality of life, as compared with the current standard first line chemotherapy. Outcomes of current therapy are relatively poor, so even small benefits are of considerable importance.

(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.

As above, for this subset of patients, improvement in survival and quality of life (symptoms, ability to functional normally etc.), as compared with current first line chemotherapy is of obvious importance. With such poor outcome overall, it is important that patients have the best chance of extended survival and good quality of life.

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).

As with all chemotherapy regimens, the balance is between benefit and treatment toxicity. Both this technology and the current treatment standard in first line, have cisplatin containing regimens.

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

Not aware of any

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?

The indication is for a histological subgroup of nsclc patients, who benefit more. Currently first line chemotherapy is the same for all nsclc histology.

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.

NICE guidance for first line (all nsclc) - Platinum based (cisplatin or cardoplatin) in combination with gemcitabine or vinorelbine or docetaxel (less commonly used in the UK) or paclitaxel (not really used in UK)

(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.)

No personal experience. However, trials show that the histological subset (other than predominantly squamous) do better with this regimen

(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)

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

No personal experience

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.

No personal experience

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

Not known

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?

Improvement in outcome for this subset of nsclc patients

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

These patients would not be able to access the treatment, unless they were able to pay for it. As lung cancer is so closely linked with smoking and with smoking having a social class skew, it is clear that this is not a patient group which are readily able to pay for treatment outside 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.

This patient group, as indicated above, have in general, a very poor outlook. In their deliberations, we hope that the Appraisal Committee will take this into account as perceived small improvements in quality of life and survival are of disproportionately large importance to patients towards end of life.