NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Ceritinib for previously treated anaplastic lymphoma kinase-positive non-small-cell lung cancer [ID729]

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, including health-related quality of life)
- preferences for different treatments and how they are given
- expectations about the risks and benefits of the treatment.

We have already asked your nominating organisation to provide an organisation's view. We are asking you to give your views as an individual whether you are:

- a patient
- a carer (who may be voicing views for a patient who is unable to) or
- somebody who works or volunteers for a patient organisation.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The response area will expand as you type. The length of your response should not normally exceed 10 pages.

1. About you

Your name: Tom Haswell
Name of your nominating organisation: ICPV
Do you know if your nominating organisation has submitted a statement?

☐ Yes ☑ No

Do you wish to agree with your nominating organisation's statement?

☐ Yes ☑ No

(We would encourage you to complete this form even if you agree with your nominating organisation's statement.)

Are you:

- a patient with the condition?

☑ Yes ☐ No

- a carer of a patient with the condition?

☐ Yes ☑ No

- a patient organisation employee or volunteer?
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☑ Yes ☐ No

Do you have experience of the treatment being appraised?

☐ Yes ☑ No

If you wrote the organisation submission and do not have anything to add, tick here ☐ (If you tick this box, the rest of this form will be deleted after submission.)

2. Living with the condition

What is your experience of living with the condition as a patient or carer?

I was diagnosed with NSCLC in 1993 and told there was no treatment which would have any effect on my lung cancer and I was given a very short life expectancy. I took part in an early phase clinical trial of gemcitibine and cisplatin which proved to have positive effect and this was followed by radiotherapy. The outcome was/is I am registered disabled, medically retired unable to work, but alive and with a quality of life acceptable to me considering the prognosis I was given. The impact of lung cancer totally changed my life, my background was in engineering and I worked overseas for many years, in fact my diagnosis was in Jeddah, Saudi Arabia and was picked up at a routine employment medical. What made it more surprising was the fact that I had no outward symptoms that would have indicated to me that I should present to a doctor yet I had a 7cm x 4cm tumour and infected nodes. As you can imagine the impact of the diagnosis on my family was severe but made many times worse when we were told of my short life expectancy, so you can see how lung cancer can affect people other than the patient. The side/after effects of lung cancer and the treatments can be considerable, in my own case, pneumonitis, pulmonary fibrosis and bronciectasis. I have been very fortunate and without being melodramatic, if I had not been given the opportunity of taking part in the clinical trial I would not be around today. Taking part in the clinical trial created an interest in me in medical research and for many years I have been involved in patient issues, service delivery and research with the emphasis on research and in particular lung cancer. I am involved in with various committees, organisations and groups which have included being a member of the NICE GDG which reviewed and updated the guidelines in 2011 and I was also a member of a NICE Expert Diagnostic Advisory Group which reported on EGFR test equipment for lung cancer patients. I was also a member of the NCRI Lung Clinical Studies Group from 2006 to 2012 and have now been reappointed to that CSG. I am also involved as co-applicant, collaborator, advisor on various research studies, many involving lung cancer and am and have been a

member of TMG's and TSC's. If further information of my background and experience of lung cancer is required, please let me know.

3. Current practice in treating the condition

Which treatment outcomes are important to you? (That is, what would you like treatment to achieve?) Which of these are most important? If possible, please explain why.

Cure and overall survival are the most important outcomes in my opinion, but being realistic and being aware of the condition, quality of life is a major factor and unfortunately some patients have got to decide in certain circumstances if they prefer a shorter life expectancy with good quality of life or longer life expectancy with not such good quality of life.

What is your experience of currently available NHS care and of specific treatments? How acceptable are these treatments – which did you prefer and why?

When I was diagnosed with lung cancer (1993) mutations such as ALK, EGFR, etc. had yet to be identified I believe so I have had no experience of targeted therapies. My understanding of ceritinib is that it is a very effective drug, more active than chemotherapy, has less toxicities and is taken orally

4. What do you consider to be the advantages of the treatment being appraised?

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

Please list the benefits that you expect to gain from using the treatment being appraised.

Further to above, my understanding is that many patients with ALK+ develop brain metastisis and ceritinib can be very effective in controlling this making it possible to limit the requirement for whole brain radiotherapy. I believe patients do very well on ceritinib but would fare much worse on chemotherapy, (side effects and anti-cancer activity). It seems patients have a much improved quality of life on ceritinib leading a much more " normal life ", being able to return to or continue working, which can ease financial concerns, much less fatigue, more energy, can play with the kids, no sickness, no chemotherapy effects. With it being an oral drug, hospital visits reduced which has all round benefits.

Please explain any advantages that you think this treatment has over other NHS treatments in England.

The comparator in the scope is best supportive care, i.e. analgesics, oxygen, blood transfusions, perhaps no anti-cancer treatment and ceritinib seems to show multiple advantages over the comparator.

If you know of any differences in opinion between you and other patients or carers about the benefits of the treatment being appraised, please tell us about them.

Don't know of any differences.

5. What do you consider to be the disadvantages of the treatment being appraised?

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)

- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)
- any other issues not listed above

Please list any concerns you have about current NHS treatments in England.

Lack of access to certain medicines and treatments for all patients. This drug I believe is available on compassionate grounds from the drug company but my understanding is that this will stop now that the drug has been licenced, it is not available through the cancer drugs fund and will not be available for NHS patients.

Please list any concerns you have about the treatment being appraised.

Care has to taken in respect of some side effects, diarrhoea which I understand can be controlled by loperamide and if required, a reduction in the dose of ceritinib. Blood abnormalities which again can be treated by reducing the ceritinib dose.

If you know of any differences in opinion between you and other patients or carers about the disadvantages of the treatment being appraised, please tell us about them.

The disadvantages mentioned above would appear to be acceptable to patients and can be controlled.

6. Patient population

Do you think some patients might benefit more from the treatment than others? If so, please describe them and explain why.

Ceritinib is a treatment for lung cancer patients with the ALK+ mutation and my understanding is that it is an ALK inhibitor and a targeted medication.

Do you think some patients might benefit less from the treatment than others? If so, please describe them and explain why.

If they do not have the ALK mutation there may be less benefit.

7. Research evidence on patient or carer views of the treatment

Are you familiar with the published research literature for the treatment?

☑ Yes ☐ No

If you answered 'no', please skip the rest of section 7 and move on to section 8.

Please comment on whether your experience of using the treatment as part of routine NHS care reflects the experience of patients in the clinical trials.

I am vaguely familiar with previous clinical trials and it seems that patient experiences reflects trial experiences.

Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?

If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?

Not available on NHS I understand.

Are you aware of any relevant research on patient or carer views of the condition or existing treatments?

☐ Yes ☑ No

If yes, please provide references to the relevant studies.

8. Equality

NICE is committed to promoting equality of opportunity and eliminating discrimination. Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, who they are and why.

Can't think of an adverse impact unless for someone who has difficulty swallowing tablets.

9. Other issues

Do you consider the treatment to be innovative?

☑ Yes ☐ No

If yes, please explain what makes it significantly different from other treatments for the condition.

Patients relapse on crizotinib and I think ceritinib is a beneficial treatment compared to what else is available, BSC, chemo.

Is there anything else that you would like the Appraisal Committee to consider?

From what I can find out ceritinib gives patients a very much improved quality of life, the opportunity to live a more " normal life " and gives them hope for the future.

10. Key messages

In no more than 5 bullet points, please summarise the key messages of your submission.

- Better quality of life
- Hope for the future
- Lesser side effects which can be controlled
- It is an effective drug for this group of patients and it would be disastrous if it was not made available for NHS patients
- Patients on this drug lead a more " normal life "