

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Follicular lymphoma - rituximab (review of TA110)

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: Andrew Barton

Name of your organisation:

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology?
YES
- a carer of a patient with the condition for which NICE is considering this technology? NO
- 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) NO
- other? (please specify)

Andrew Barton
25/7/11

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Thank you for allowing me the opportunity to contribute to this process. I have chosen to submit a Patient Expert Statement, but would like to confirm that I fully support and endorse the statement prepared by the Lymphoma Association in this regard.

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.

I anticipate that the use of this technology to provide me with an increased length of remission and a more effective treatment for my NHL. As someone who was diagnosed with the disease at the age of 47, and who had treatment at 48, anything that can provide better treatment is of a great benefit to me, my family and society as a whole, through allowing me to continue working and paying taxes.

(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.

Improvements in treatment and the use of this technology lead to longer remission periods. This has a huge beneficial outcome for the patient's quality of life, their mental health and is of great benefit to those around them. By using sophisticated, targeted treatments such as this, side-effects are kept to a minimum, but effectiveness is improved. The disadvantages, such as a slightly suppressed immune system, are far outweighed by the advantages, in my opinion.

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:

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- 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 am fortunate in being a relatively young patient, physically fit apart from my NHL. Therefore, I haven't suffered from too many side-effects as a result of the treatment and none directly attributable to the Rituximab. My family have been heartened to know that I am receiving the current Gold Standard of treatment for this condition and I am also fortunate in that I have a very understanding and supportive employer

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

I know several people who have received either R-CVP or R-CHOP and none expressed any complaints to me about the Rituximab element of the treatment

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?

I am not a clinician, but for those people suffering from the relevant NHL, it seems to me that everyone would benefit from this technology, unless there are contra indications in other aspects of their health

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.

The addition of Rituximab to CVP and CHOP would appear to have greatly improved its efficacy.

(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

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hospital)

- side effects (please describe nature and number of problems, frequency, duration, severity etc.)

The technology does improve treatment and, given that it is administered at the same time and via the same method as the standard chemotherapy treatment it does not really disadvantage the patient at all. With the use of anti-histamines and paracetamol, my understanding is that for the vast majority of patients, it is extremely well tolerated.

(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).

From a personal point of view, I can see no real disadvantages associated with the technology.

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.

I cannot comment on this aspect.

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

I cannot comment on this aspect.

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.

I cannot comment on this aspect.

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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?

This technology has been available on the NHS for several years now and has become the standard treatment for patients with follicular NHL. It has improved remission periods, improved the efficacy of the chemotherapy element and generally improved the short and medium term outlook for the patients receiving it.

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

The opposite of the above

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

I cannot comment on this aspect.

Other Issues

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

None