NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Aflibercept for the treatment of metastatic colorectal cancer which has progressed following prior oxaliplatin-based chemotherapy

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: [redacted]

Name of your organisation: patient

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)

other? (please specify)
I was diagnosed with a single metastastic lesion in my liver at the same time of my diagnosis with a colo rectal tumour in July 2008 [T3. M1. N1]. The lesion was treated with radio-frequency ablation after

- **chemotherapy [oxaliplatin, fluorouracil, folinic acid]**
- **combined radiotherapy and oral chemotherapy[capecitabine]**
- **surgery [abdominal-perineal resection, T.M.E., rectus flap, and perineal skin graft]**

No other lesions have presented themselves since then.
Background

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1. **social.**
    - **62 year old single woman.**
    - **One daughter, Georgina [41].Three grandchildren, Daniel [24], Madelaine [22] and Jacob [19]. One great grand daughter, Harriet [11 months].**
    - **Volunteer for Charing Cross Hospital Macmillan Service**
    - **Facilitator for Shepherd's Bush Stoma Support Group.**
    - **Keen gardener**

2. **Professional**
    - **Registered nurse, mostly working with people with life limiting conditions, for example cancer supportive care services, and H.I.V. supportive care services. [1971 – current date]**
    - **Counsellor, setting up and providing counselling services for people with chronic kidney failure, and their families. [1992 – 2010]**
    - **Independent assessor for The Human Tissue Authority [2010 current date]**
    - **Counsellor for The British Kidney Patient Association [2011-current date]**
3. **Health**

    Under review from oncology services

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.

The great advantage of this treatment is that I hope it would be more final and more effective than ablation.

(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.)

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- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

Currently, I feel that I am in a situation of simply awaiting the development of another lesion. This is challenging, psychologically as well as physically.

- **It affects my quality of life - at times it is difficult to maintain enthusiasm and buoyancy in my being, and I experience low mood. Having frequent regular scans seeking evidence of metasteses in order to treat speedily are both reassuring and equally keep me focused in the here and now on the great uncertainty of my health and life.**
- **It affects decisions about working - for example I am self employed and now only commit to one year contracts at a time**
- **It affects decisions about pension and saving issues**
- **It affects my daughter in terms of the uncertainty of my future health and her support of me.**

In the light of these existing factors, the advantage of a new treatment that may be more effective in treating metasteses, would be of great advantage to me, reducing the stress, burdens and short term planning that currently frame my 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).

I am unable to comment upon the first two aspects of the treatment.
As for side effects, for myself there is a balance, which does fluctuate according to my stamina, resilience and motivation, of living with side effects and the importance of having access to help, advice and medication/ treatment, particularly from specialist nurses and the M.D.T.
The impact upon my work would be an issue, time off on unpaid leave, the cost of living and issues of prescription charges and pharmacy bills.

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The impact on others, particularly friends and family, is potentially intrusive in terms of time and money. Time off work to assist with travel to hospital and the inevitable 'neglect' of other members of the family for periods of time would be an issue.

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

The usefulness of a treatment, is loaded with personal issues, not only for different patients, but for different times in a patient's life. After undergoing the treatment for the primary cancer, a level of understanding of the physical, psychological, social, financial, and family impact is developed. The experience of the treatment, the staff, the centre facilities etc will be a factor. All future treatment options will be viewed through the lens of this and other subsequent treatments.
The usefulness of a treatment will also at some level be weighed against my evaluation of the usefulness of my life.
At the moment I am highly aware of the financial stress the N.H.S. is under and this impacts on my thinking – for example when I see younger patients and wonder if there could or should be limits to treatments for metasteses and if so, should age be a deciding factor.

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?

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.

(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,

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duration, severity etc.)

My hope is that the treatment will mean a better outcome in terms of prognosis, length of life, and the subsequent effects upon the patient and their family.

(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).

Whether there is one lesion or many recurring frequently, I think it is crucial to involve and enable the patient to have a realistic and collaborative relationship with the M.D.T. so that decisions regarding treatment, particularly in the issue of futility are as openly and respectfully raised and addressed.

Equality and Diversity

NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- Could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- Could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- Could lead to recommendations that have any adverse impact on people with a particular disability or disabilities

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts

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.

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

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.

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?
The key difference would be to extend the range of treatments for metastastic colo rectal tumours and this would I hope affect outcomes positively.
What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?
If this treatment was not on offer then outcomes for patients would be unchanged, and the opportunity for valuable clinical experience on the part of the M.D.T. would be lost.

Are there groups of patients that have difficulties using the technology?
I wonder whether patients with comprehension or cognitive difficulty would be very challenged by this process of contributing?

Other Issues

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

Jacqueline fraser
07.05.2013