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:

Brenda Brady

Name of your organisation (if applicable):

Mouth Cancer Foundation

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?
- 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.

Control of spread of cancer: The phase III trail in the US seems to suggest that Erbitux in combination with chemical or radiotherapy has a significant impact on the control of cancerous cells.

Improving the quality of life: This drug would give renewed hope to patients with head and neck cancers with the prospect of living an independent and fulfilling life.

Prolonging life: The evidence from the trials would also suggest that life is prolonged significantly for those who took Erbitux.

(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: Insufficient trials have been undertaken in this country to form an opinion.

Physical symptoms: my understanding is that the side effects are: acne rash, fatigue/ malaise, cold/flu symptoms and nausea.

Pain: no knowledge

Level of disability: no knowledge

Mental health: No knowledge

Quality of life (lifestyle, work, social functioning etc.): Short and long term benefits anticipated

Other quality of life issues not listed above: Offers hope to patients with advanced head and neck cancers.

Other people (for example family, friends, employers): By definition, these people with benefit from the patients improved health.

Other issues not listed above. none

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).

It is my experience, as an active user of the Mouth Cancer Foundation website, that most patients with advanced head and neck cancer would be prepared – and indeed willing – to tolerate the actual or perceived side effects. These include skin rash, fever, chills, fatigue and nausea. I understand that skin rash is the most common side effect and its severity is an indication of the effectiveness of the treatment; therefore, patients would positively welcome the rash.

The impact on others, eg family, friends and employers, would not change as the patient would already have a level of disability associated with the cancer.

The financial impact would be negligible.

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

As the technology is not yet available in this country I cannot answer this question with confidence; although the American studies, as described on the Oral Cancer Foundation website, seem to show a consensus about a willingness to try the technology with favourable results

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?

Until trials are carried out in the UK and the findings are made known, I cannot comment

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.

Surgery is the principal means of treating head and neck cancers. It can have a severe impact on the quality of life. Surgery is often done first since complete removal of the tumour is a possibility, and surgical reconstruction and healing are unimpaired if the soft tissues have not previously been irradiated. Radiotherapy is often administered after surgery to kill off any recalcitrant cells; but the high doses of radiation required for effective control have significant side-effects.

If surgery is not appropriate then radiotherapy and possibly chemotherapy could be the selected treatment.

(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.)

The US trials show very positive results with tolerable side effects and in general an extended quality and duration of life.

(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 my reading of the experiences in America, there appears to be no worsening of the overall condition or specific aspects of the condition.

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.

Not familiar

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

Not applicable

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.

The MCF polled its members and 100% of the 21 members who voted said they supported this treatment being made available to head and neck cancer patients. Reference: MCF Poll of patient views: http://rdoc.org.uk/eve/forums/a/tpc/f/19510549/m/9921081421/showpollresults/Y

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?

At a fundamental human level, it would offer hope to most patients (and carers) who wish to see medical advances in the treatment of this somewhat low profile cancer that has not had any significant improvement in 5-year survival rates over the last few decades.

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

It would reinforce the view held by many that the Government and NHS does not give priority to medical research and development in head and neck cancers; despite the fact that they are amongst the top five most prevalent cancers in the UK.

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

Patients who have an allergy to cetuximab or mouse protein may not be able to use Erbitux.

Other Issues

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

Surgical treatment of this cancer can have widespread and devastating consequences for many aspects of a patient's life style. For example, in my case, I have undergone two major operations and one gamma knife treatment. The operations were to remove my lower jaw bone and replace with bone from both legs and held in place with titanium. Also half of my tongue has been removed and replaced with soft tissue from my forearm. In addition I had a radical neck dissection. The gamma knife treatment was to remove a tumour in my skull.

The consequences are a) my face is disfigured; b) my speech is affected; c) I cannot chew food which means I have a pureed diet – this in turn curtails my social life and holidays etc; and d) each day presents varying levels of pain.

These and other side effects (i.e. radiation burns, dry mouth, trismus) are part of everyday life for the people who I frequently correspond with on the Mouth Cancer Foundation website.

The social consequences of mouth cancer cannot be hidden away.

Despite all this, I still value each additional day I live.