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:
Jean Fraser

Name of your organisation (if applicable):
National Association of Laryngectomees Clubs

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)
volunteer/member

- 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.

Affect the outcome for patient – It would appear from the documentation that there should be improvements in the long term survival rates for Head & Neck Cancer using the treatment regime proposed

Improving the Quality of Life – early diagnosis and use of this treatment should hopefully reduce the need for surgery, the cause of most disabling effects of treatment, to a minimum.

(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,
  improved treatment regimens for patient group identified
- physical symptoms
  a general reduction in the physical symptom to levels which could be reduced by the use of recognised therapies, including alternative regimens
- pain – should those already affected by neurological symptoms be excluded from the trials there should be no increase in pain levels
- level of disability,
  early diagnosis together with the treatment regimens proposed should reduce the range of disabilities normally associated with the condition.
- mental health reduction in the disabling effects of treatment should also reduce the risk of mental health in this patient group
- quality of life (lifestyle, work, social functioning etc.)
  it would seem from the literature that treatment using the proposal described will lead to major improvements in most aspects of the quality of life
- other quality of life issues not listed above
  recognition that there will be significant improvement in levels of individual personal safety
- other people (for example family, friends, employers)
  family have difficulties in fully comprehending, and may question whether the patient will require additional support should be encouraged to take a long term view, informed peer support may be crucial in this area

other issues not listed above.

maintenance of communication methods should be a priority for the professionals supervising the treatment.

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).

The technology could increase the effect of damage to the skin, as the result of the rash. Although by increasing the patient's recognition of the positive outcome of the treatment that these symptoms indicate the clinician may increase the patient's willingness to cooperate.
New pathways for patients being trialled, may in some cases reduce the financial burden of treatment schemes by having caring and transportation available throughout the days and weeks of treatment,

There is a need however to recognise the difficulties some rural patients, or those residing at considerable distances from the treatment centre may face, in particular the financial implications. It should be recognised that laryngeal cancer patients faced great difficulties in accessing benefits particularly those related to disability.

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

Some patients noted that there were no comments made in the proposals which indicated that genetic, occupational or environmental related issues have been factored into the equation when deciding whether the proposed treatment regimens as suitable for individual patients.

Others noted that appeared that improvement in overall survival for laryngeal cancer patients is less clear than for others in the study.

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?

It is reported that oropharyngeal cancer patients appear to derive more benefit whilst laryngeal and hypopharyngeal patients gain less benefit, but this needs to be confirmed by UK results.

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.

Laryngeal cancer treatment, and indeed outcomes appear linked to diagnosis timing. Those patients presenting with early stage carcinomas may well receive radiotherapy alone, if reoccurrence of the cancer occurs surgery may follow. However as a result pf radiotherapy there may be difficulties in the healing process.
Patients presenting later will undergo surgery first followed by radiotherapy 'mopping up', the impact on the patient, and family, of coming through major traumatic surgery only to face more treatment at a time they are beginning to recover should not be underestimated.
Both scenarios have benefited from the use of localised laser 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.)

It would seem that this treatment has the potential for major improvement is in the long term survival rates. Home treatment technology which reduces the need for travel can only assist recovery.

(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).

Use of tablets for this group of patients may present difficulties due to damaged or reconstructed swallowing mechanisms.

There is a very real risk however for these patients that they may become

reclusive, hospital visits i.e. Speech and Language Therapist support can reduce the impact of the self image problems.

Caring for patients at home during treatment does however place additional strain on untrained or unsupported Carers; this can be reduced but not eliminated by good primary care support. Peer group support if available should not be underestimated.

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 aware of any relevant information

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.

DAHNO & NICE guidelines for the treatment of Head and Neck Cancer which includes mention of NPSA advice on the care of neck breathers has improved professional post operative care. However airway safety of laryngectomees remains a priority for carers supporting Laryngectomees in the community.

NALC has consistently welcomed any research leading to improvements in treatment, and outcomes, particularly those which potentially could removes the necessity for surgery which result in patients facing 6 basic disabling conditions. We are told that a UK centre has provided radiotherapy treatments over a 7 day cycle and understand that some regimens, which appear similar to those described in the data as 'hyperfractionated', may have been trialled

Patients, and their families, will welcome any treatment which may prolong life. They would expect to be able to identify clear benefits from a regimen which has not trialled specifically on the cohort of patients for which the appraisal is made, nor appears to fall within the parameters of the agreed UK, or Europe wide, radiotherapy treatment. Professionals and patients will seek to establish, as part of their partnership, confidence that this treatment will bring about the best outcomes of health related quality of life.

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?

For those patients for whom it would be beneficial, this treatment could improve both their quality of life and their life expectation, something long overdue for this group of cancers, which have such a low profile.

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

For many patients lack of availability would be seen as reinforcing their views that H&N cancer is seen as self inflicted and impact could on their self esteem.

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

There may well be patients unable to tolerate this product.

Other Issues

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

Some additional support facilities, particularly for those patients living alone, may be required to facilitate these treatment regimens, this should be factored in to the initial costings.