

Patient/carer organisation statement template

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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: Mrs Marie Wilby

Name of your organisation:

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)

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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).

In my case, side effects not pleasing but tolerable

Skin on face and upper body like acne – Not on the area treated with RT

Tongue splitting and ulcerated

Thinning of skin on fingers and heels causing painful splits

Nausea

Fatigue

Difficulty in Sleeping

Flatulence, stomach cramps and Diarrhoea

Dry mouth

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

Not Known

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?

Not Known

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.

Herceptin, but this drug did not cover the body/brain barrier
Not so invasive as Radiotherapy

(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.)

In my case, overall improvement and reduction in brain tumours. Other tumours under control (i.e Liver, Spine, chest & Ribs)
Easy to use at home being in Tablet form

5)

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(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).

Skin on face and upper body like acne – Not on the area treated with RT – Always present but some weeks better than others

Tongue splitting and ulcerated – Tongue is always split and it does get ulcerated when eating foods deep fried

Thinning of skin on fingers and heels causing painful splits – happens regularly

Nausea - occasional

Fatigue – when walking uphill or going upstairs

Difficulty in Sleeping – Occasional

Flatulence, stomach cramps and Diarrhoea – Diarrhoea usually 2-3 times daily,

flatulence less often than at the start

Dry mouth – Less often than at the start

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 with any evidence

6)

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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?

Not known

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.

Not known

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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?

The key difference would be that patients unfortunate enough to have secondary breast cancer in the brain would have a procedure available which would prolong and give an improved quality of life.

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

If not available, Patients would die earlier than they needed to.

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

Not known

8)

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Other issues

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

It is a lifeline when all other medications have failed