

Patient Expert Submission Template

Thank you for agreeing to give us a personal statement on your view of the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on what they would like from a technology, which is not typically available from the published literature.

To help you in making your statement we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. A short, focused reply, giving a patient's perspective, is what we need. Your statement can be as short as you like, and we suggest a maximum of 4 pages.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. Advantages

(a) Please list any aspects 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.

For people with advanced or secondary breast cancer Gemcitabine used as a single therapy could provide an option or choice of further chemotherapy to try and increase survival and reduce disease related symptoms. This potentially could have a positive effect on a person's choice of treatment and quality of life.

In combination (as licensed with paclitaxel) to improve both response to treatment and survival in this group of people.

(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.

From the experience of women contacting Breast Cancer Care while all treatments will have some side effects, this generally appears to be a well tolerated treatment which should then balance quality of life against the aims of offering treatment. This is often an important factor for both patients and families when making the decision to accept further treatment or not.

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 (see list in (b) above for suggested items)
- 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 or their family (for example cost of travel needed to access the technology, or the cost of paying a carer).

Anecdotally, from speaking to women single agent gemcitabine seems to be not often available or offered within the NHS but it is an option when people are treated privately. However, the decision to offer treatment has to be based on clinical assessment and not offer false hope to people with advanced or secondary breast cancer.

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

Not aware

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?

This could be a relevant treatment consideration to all people with advanced or secondary breast cancer as possible first line, second line or salvage treatment based on clinical judgement .

The advantages and disadvantages of the technology compared with current standard practice

NICE is particularly interested in your views on how the technology compares with current standard practice (alternatives if any) used in the UK.

Please list any alternatives available as far as you are aware in current standard practice to the technology

(i) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe. Advantages might include:

- improvement in the condition overall or in certain aspects of the condition
- ease of use (for example tablets rather than injection, at home rather than in hospital)
- fewer side effects (for example number of problems, frequency, duration, severity)

As mentioned in (1i) Gemcitabine appears to be well tolerated with its profile of common side effects similar to other drugs such as capecitabine/vinorelbine. Side effects in palliative chemotherapy is an important deciding factor for many people and their families.

(ii) If you think that the new technology has any **disadvantages** for patients compared to current standard practice, please describe. Disadvantages might include:

- inconvenience of use (for example is it a treatment that has to be given by somebody else or in hospital?)
- more side effects (for example number of problems, how often, for how long, how severe).

The disadvantage of travelling to hospital outpatient visits for intravenous administration may be difficult for some people with advanced or secondary breast cancer when any oral preparation may be considered more appropriate.

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.

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

Any additional sources of evidence?

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 [or, please attach copies of the study report]

Implementation issues

Is the following an implementation issue or should we change heading?

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS? [Although the best response to chemotherapy is generally with first treatment...using gemcitabine\(combination\) appears to improve this. However, single gemcitabine could also add to the possible treatment options for people with advanced or secondary breast cancer.](#)

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

Breast Cancer Care is an organisation providing information and support and we enable people with breast cancer to speak to others with a similar diagnosis. If we have a situation when treatments are available privately but not on the NHS this creates concern from people about inequalities in health and distress at a very difficult time.

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