

Patient/carer organisation statement template

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: XXXXXXXXXX

Name of your organisation: PromoCon

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)**

Team Director

- other? (please specify)

A clinician Specialist nurse

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.

Management of intractable constipation when the only other option is rectal administration which many women do not find acceptable

(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.

Earlier resolution of the problem
Can be carried out in patients home

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).

Some studies have reported high rate of reported side effect (80%) the most frequent being headache, nausea, abdominal pain and diarrhoea. There is also an apparent reported small risk of cardio vascular adverse events. However most of the side effects were transient and mild to moderate in severity although diarrhoea was the most likely cause of discontinuation of treatment

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

I am not aware of any

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?

The group who may benefit most are those in whom all other oral laxative treatment have failed to resolve the chronic constipation and associated problems

Those less likely to benefit are those whom standard treatment for constipation is effective

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.

Movicol with or without an added stimulant

(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.)

Oral treatment as opposed to rectal when standard treatment fail

(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).

Disadvantages – side effects although not severe can be debilitating and potentially life threatening

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.

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?

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

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

Other Issues

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

Constipation is often considered as a 'trivial' problem by the medical profession and not considered a significant problem. As a result many individuals suffering with constipation self treat and buy over the counter medication with little robust advice regarding appropriate dosage and length of treatment. As a result many patients suffer for years allowing the condition to become chronic. More emphasis should be placed on ensuring appropriate treatment when constipation is in the acute phase - alerting pharmacists to offer appropriate advice when OTC laxatives are bought would go a long way to prevent this problem escalating and the need for relatively expensive 'rescue' medication. The soon to be published NICE guidelines regarding Idiopathic constipation in childhood will provide appropriate guidance regarding the use of laxatives dosages and treatment time. There appears to be a need to also educate healthcare professionals regarding the treatment of constipation in adults – the continued inadequate management in the acute phase (including over cautious use of laxatives in inadequate dosage) will only result in the number of patients developing chronic constipation
Increasing