

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: Stuart Berliner

Name of your organisation: The National Association for Colitis & Crohn's disease (NACC)

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)

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.

I have been a sufferer of ulcerative colitis for 30 years (mostly in remission after the first few years, with occasional mild flare-ups). The condition was initially diagnosed as proctitis until 3 years ago when it developed in to pan colitis. I have had frequent flare-ups in the last 1½ years. Treatment with steroids led to side effects and so I am now on Azathyoprine. However, I am veering from Mildly Active UC to Moderately Active UC. I anticipate that in these circumstances, I may have to contemplate the possibility of a colectomy in the future.

As someone who enjoys an active working, social and sporting lifestyle, the threat to my quality of life is very real and I would want to explore **every** opportunity to avoid surgery and reduce the frequency and severity of flare-ups that I am likely to experience. Based on my limited knowledge, it is possible that, should it be recommended by my gastroenterologist, treatment with Infliximab could considerably improve my chances of avoiding surgery and the subsequent reduction in quality of life that this would bring.

(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.

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).

I would be concerned with any potential side effects and would need to receive and consider carefully advice on what these are.

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

Do not know.

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?

Do not know

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.

Unable to comment

(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.)

Unable to comment

(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).

Unable to comment

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.

Unable to comment

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

Unable to comment

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.

Unable to comment

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?

It would offer a further and possibly better opportunity of avoiding or delaying the necessity of surgery.

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

It would restrict the range of treatments available to fight this debilitating and potentially seriously disabling illness

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

Unable to comment

Patient/carer organisation statement template

Other Issues

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