

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: [REDACTED]

Name of your organisation: **Hepatitis B Foundation UK**

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) Co-ordinator /CEO
- 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.

The advantage is that the drug will give those patients who have developed resistance to the other therapies a chance to live and not develop serious liver disease

(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 as mentioned above
- physical symptoms reduces the physical symptoms
- pain helps reduce associated pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.) means patients can get back to work and live a normal life and contribute to society
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

All research in other EU countries shows the earlier an intervention is made with treatment the more cost effective it is dealing with end stage liver disease is painful needless and expensive

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).

As this is an oral therapy patients find it easy to use and comply

Reduces cost of expensive trips to hospital

The only concern is that some patients will develop resistance to this therapy

Which is why patients need as many choices as possible to overcome that problem

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

No patients are very very pleased to a choice of therapies

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?

All patients might need this therapy

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.

There are other oral therapies which many patients have developed resistance to This oral therapy is much better than having to self inject for 48 weeks as is the case with Peg-interferon

(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 YES
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection) YES
- where the technology has to be used (for example at home rather than in hospital)USED AT HOME
- side effects (please describe nature and number of problems, frequency, duration, severity etc.) VERY FEW DIFFERENT FROM PATIENT TO

PATIENT

(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).

No DISADVANTAGES

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.

YES IT DOES

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

NOT TO THE KNOWLEDGE OF THIS PATIENT GROUP

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.

European Orientation Towards the Better Management of hepatitis B in Europe

Recommendations of the Hepatitis B Expert Group

Chaired by Dr T Ulmer MEP

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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?

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.