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: Anil Patel

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)

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.

This technology suppresses the virus and extends my life, taking this drug has let me move on with my life and career.
Letting me continue living a normal life, this has enabled me to pass my MSc and progress my career in Chartered Surveying.

(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.

Extends my life and gives me the best chances when there is a cure found. I can forget about my illness and carry on a normal life. No side effects with this technology, one pill taken orally so simple to administer.

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).

This drug is very expensive to take outside the NHS if they will not provide in certain areas. I have to travel to the Hospital (7 miles each way) to get these drugs every 3 months, if people are disabled then this might be very difficult and time consuming.
The hospital is only allowed to dispense 3 months only, making me visit the hospital every three months, which costs the hospital money to dispense and other administration costs.

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

I think this drug is the best technology I have used and has helped me hugely as I am now able to concentrate on my life, before it was very depressing getting results every three months, knowing if the other technology's is not working and making my illness worst. Now this technology enables me to continue to live my life knowing my illness is being controlled.

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?

None

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.

Lamivudine, Adefovir and combination of the two

(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.)

I have no side effects with this technology; my condition is being controlled and stable. One table to take instead of two, for the combined therapies.

(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).

It is not available on the NHS, and is very expensive and time consuming to get hold of this technology.

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.

Do NHS clinical trials take into account the life improvement of patients so they can get on with their lives and concentrate on other things like family and careers.

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

No side effects with me.

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.

No

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?

I would be so happy I could get this technology as it is working and helping me extend my life so I can continue on living a normal life. The cost benefit would be huge for patients and the NHS, less travel for patients and the ordeal of visiting hospitals for collecting drugs which can be given my a local GP. The NHS would benefit by less patients coming in for drugs and administration cost and time. I would like to highlight an important fact that I have caught more illness visiting hospitals due to more sick people being around, than a local GP surgery or visiting a pharmacy. This would easy the heavy strain on the NHS treating fewer illnesses picked up from non urgent visits to hospital. The other benefit would be if I was ill and need to get this drug, I may spread my illness just coming to hospital to collect. More strain 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?

I would need to pay for this drug my self, and would need to sell my house, just to fund this expensive drug. If I couldn’t pay for the drug, I would need to come off the drug and may get resistant to the drug and other technologies, which would mean I would die.

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.

This drug is working of me and it has taken me 5 long years of tests after tests, hospital visits after hospitals visits and worry about results to get here. It’s only the last two years (after taking this drug) I have been able to move on with my life and continue to live as a normal human as the only wish I have been wishing for. This technology has helped me build my life so I can continue my career and education. I have been able to pass my MSc and get promoted at work. I with my wife have been able to plan for the future so we could lead a normal life just like any health human being. By not approving this drug could mean I with other patients may die knowing there is a drug which works and extends their lives is only available if we pay for it ourselves.