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: Derek Elston

Name of your organisation: ITP Support Association

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)***
  Patient with ITP
-
- other? (please specify)
- a volunteer of a patient organisation that represents patients with the condition for which NICE is considering the technology

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.

Derek Elston Satement.
The existing treatments available do not always alleviate symptoms in every patient and side effects are evident with many existing therapies. It therefore follows that any additional treatment is welcomed by patients especially if this would entail self administration with the benefit of an increased platelet count.
Another benefit from this drug would be the removal of concern expressed by general practitioners and/or registrars, with little or no experience in dealing with ITP. ON many occasions I have been advised to undergo splenectomy with no certainty of success either in the short term or long term.
Other advantages would be the management of the platelet count at a reasonable level thereby reducing the risk of sudden drops and resultant bruising and haemorrhage.

(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
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

Derek Elston statement.

The benefits gained by the patient in a self administered drugs are many. Firstly the cost to the patient in monetary terms could be substantial and the need to attend clinics on a regular basis is removed. This would be a direct cost saving for travel apart from the time factor which for employed people could be high. In addition, the cost saving for the hospital trust could also be substantial.

There will probably be little or no benefit for the long term outcome of the condition.

Bruising is always a concern for people with ITP especially where it is clearly visible and could be construed as physical harm. Any assistance for such people would be appreciated.

2. Disadvantages
Please list any problems with or concerns you have about the technology.

Derek Elston Statement.

I am unaware of any side effects to this technology.

Patients will need to be educated in self injection and this may prove difficult to certain patients

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

Derek Elston Statement

I am unaware of any patient not wishing to see new drugs being available as treatment using current drugs is very much trial and error until one is found that has an affect upon the platelet count.

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?

Those patients who would benefit are those :-
1. Who suffer with extreme side effects from current therapies.
2. Who have no or minimal benefit from current therapies
3. Who have life- threatening bleeds.

Comparing the technology with alternative available treatments or technologies

NICE is interested in your views on how the technology compares with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

Derek Elston Statement.

Since being diagnosed with ITP, I have undergone treatment from the following drugs/therapies.

-Prednisolone, dexamethosone (steroid)
-IVIG (immunoglobulin)
-Anti-D (immunoglobulin)
-Azathioprine immunosuppresant
-Platelet transfusion

Additional information

The only treatment apart from platelet infusion, that has been effective is immunoglobulin. This originally was undertaken on a quarterly basis by infusion. As the condition deteriorated, treatment was increased to a monthly infusion and eventually this became a weekly infusion. The overall treatment was time consuming and costly both for me as a patient and also for the hospital. Normal treatment taking one day to administer. It raised my count from around 10 to an acceptable level usually around the 350, but this very quickly returned to around 10.
I refused a splenectomy when it was offered on the basis of major surgery was necessary with no guarantee of success and a life of antibiotics treatment thereafter.

(ii) If you think that the new technology as any advantages for patients over other current standard practice, please describe them.

Derek Elston Statement.

The only advantage I can perceive is self administration saving time and expenses for both the patient and the hospital.

(iii) If you think that the new technology has any disadvantages for patients compared with current standard practice, please describe them.
Derek Elston Statement.
I am unaware of any disadvantages at time of submission of this statement.

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.

Derek Elston Statement.

I understand this treatment is not yet used in patient care.

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

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.

Derek Elston Statement.

The only research that has been undertaken to my knowledge was that undertaken by the ITP Support Association last year. The results of this research have not yet been published, but provide the views of many sufferers and highlight the ignorance of the general medical profession and associated disciplines, surrounding this condition. It also highlights the difficulties encountered by ITP sufferers in securing insurance and life style changes necessary in certain cases.

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 were made available on the NHS?

Any new treatment would be welcomed by patients if it meant reduction in costs and easier administration***.***

What implications would it have for patients and/or carers if the technology were not made available to patients on the NHS?
It would mean those patient suffering from ITP could be faced with continued bleeding, bruising and major infections due to immunosuppressive drugs being administered.

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

Those who would find self administration difficult.

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

I have suffered with ITP for over 12 years having contracted a virus in the far east whilst on business.
In the outset, various treatments were tried before immunoglobulin was used to regularize the count. Over time, the count dropped more quickly and eventually, I was being treated with immunoglobulin on a weekly basis. This was extremely costly for the NHS and inconvenient for me as my business required extensive travel worldwide.
Since treatment has stopped, I have suffered one serious 16 hour bleed only stopped with an infusion of platelets after a long infusion of immunoglobulin. I am fortunate that I do not bruise as much as many, but have of necessity, amended my life style to try and avoid situations that could be harmful. My count is consistently around the 10 level but occasionally has reached 20 and on one occasion 50 for no apparent

reason.
I am screened every six months by my consultant with express instructions to admit myself to the haematology ward direct if a bleeding should occur. I also carry a medical card in case of emergency.