

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: Angela White

Name of your organisation: N/a

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.

(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).

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

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?

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.
- (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.)
- (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).

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.

I support the National Osteoporosis Society's patient/care expert statement on all the above issues.

I would like to add the following information about my personal experience.

When I was in my thirties I was made aware of the fact that I had low bone density as I was part of a control group when my son was on growth hormones. I was advised to eat a healthy calcium-rich diet, do weight bearing exercises and avoid smoking and excessive alcohol. I have followed this advice and play tennis regularly as well as going to the gym and doing pilates.

In spite of my best efforts, I still have a T score of -2. When I became menopausal I went on HRT for several years but after five years the doctors suggested that I should come off it because of the increased risk of breast cancer. In order to protect my bones I was prescribed Alendronic Acid which I took for one month, but suffered acute acidic symptoms and stopped taking it. My rheumatologist then suggested that I have an annual infusion of Aclasta (Zoledronic Acid), the first one of which I had last February. I must say that the side effects were most unpleasant for several days – flu like symptoms and achy joints, but after this I returned to normal and am now planning my next infusion in a few weeks.

At this point I don't know if my bone density has improved since it was last checked in 2008, but I believe it will be checked in another year or two.

I am very well aware of what life is like with osteoporosis. My late mother, grandmother, aunt, uncle and many of my great aunts all suffered with this crippling disease. In the last few years of my mother's life, every little fall resulted in a fracture or a break in her bones, she became more and more bent and ended up at 4'8" having previously been 5'4". Her body shape became that of a question mark and she was hardly able to hold her head up, as well as suffering from great pain.

From my point of view, if I can do anything to avoid ending up like my mother and other relatives, I will do so. If there is new medication to help prevent this ghastly condition, it should be made available as widely as possible. The A & E departments of the hospitals would have far fewer broken bones to fix if the incidence of osteoporosis could be reduced, and quality of life would improve drastically for many people in later life.