

Patient Expert 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: 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.

Improving symptoms of schizophrenia or psychosis such as hallucinations and delusions. For some people it may make their symptoms less distressing or relieve them completely.

Given that it has a slightly different receptor profile, it may work for some people where other antipsychotics have not.

It may have less side effects for some people, making it the drug of choice for them.

(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.

If it is the right medication for an individual, they may be able to lead an ordinary life in the community while having fewer side effects. All aspects of their quality of life may improve including social relationships with family and friends. I interviewed a young woman for a job last month who was on aripiprazole and she said it was the first antipsychotic that worked for her. Previously she had been hospitalised long term. She did not get the job but I have seen her since and she seems to be doing very well.

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).

Some individuals may find this medication gives them a lot of side effects and does not work any better than any other antipsychotic. Side effects I have heard people talking about are nausea, generally not feeling physically good ('it made me feel shit') and feeling very agitated (to the point that they being given benzodiazapines). This was obviously quite severe because the people concerned changed from aripiprazole to another drug quite quickly. Some people just went back to what they were on (including clozapine). I get the impression that their symptoms had been helped, it was just the side effects that were causing problems.

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

Some people find it a drug that they can live their life around and some people find it awful.

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?

It should be an available choice like all other antipsychotics currently approved in the UK.

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.

Currently people with schizophrenia should be offered one each of a first and second generation of antipsychotics then clozapine. This should be done in collaboration with the patient and the discussion should include what side effects someone can tolerate or want to avoid. If the person is having trouble with a medication it should be changed after a reasonable trial.

(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.)

It increases the choice of medication available.

(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).

I can't see any disadvantages, unless some clinicians start to think it's 'the drug of choice' for everyone because it's new-ish and has not been yellow carded as much as the others.

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.

I have read the Cochrane review on aripiprazole compared to typical antipsychotics. The medication looks promising for some people. However, these trials were all quite different from each other - they had varying settings, enrolled different groups of people, were for several lengths of times (from 24 hours to 52 weeks) and compared aripiprazole to different first generation antipsychotics. This made it difficult to compare outcomes from trial to trial. This chimes with what I've heard people say – it is good for some but not others.

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

Agitation.

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.

Any quality of life data was not good enough to include in a Cochrane review.

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?

More choice

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

Less choice.

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

If their side effects are bad then yes.

Other Issues

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