

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: 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) Governor SEPT, Chair Bedfordshire XbX Group, member NIMHE psychosocial interventions implementation group

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.

Positive symptoms (delusions, hallucinations and thought disorders). It is possible for this technology to alleviate or prevent these.

Negative symptoms (flat or blunted affect and emotion, poverty of speech, inability to experience pleasure, lack of desire to form relationships, and lack of motivation). It is possible for this technology to alleviate or prevent these.

Can also alleviate acute mania and mixed manic depressive states where these are present in schizophrenia.

Side effects. Less likely to produce EPS than older (typical) antipsychotics e.g akathisia
Weight gain. Less likely to produce this.

Plasma glucose levels unaffected so low risk of diabetes.

Low level of adverse cardiovascular effects. No increase in prolactin levels

(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.

Schizophrenia is a severe mental disability which Aripiprazole can control, alleviate and completely remove provided the prescribed dose is adhered to and this may be required for some years. Provided no undue side effects are suffered which force the patient to stop the medication they can return to the life they had before they became ill

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).

For a 16-18 year old sexual side effects can be particularly distressing and the patient should be educated about possible side effects before taking the medication. Various EPS can be intolerable and akathisia in particular has been linked with suicide. Family and friends are affected in that they “get back” the friend or family member they had before

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

Yes. A patient who has not been educated about side effects before first being given an antipsychotic can maintain a blanket adverse impression of antipsychotic drugs.

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?

Yes those who are genetically predisposed to less side effects from this technology will benefit more and vice versa. In addition and for example patients who put on weight with other treatments may benefit from this one.

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.

Risperidone

Olanzapine

Quetiapine

Ziprasidone

Clozapone (all atypical)

Some patients will prefer a typical treatment

Appendix D – Patient/carer expert statement template

(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.)

Generally produces no weight gain

No increase in serum cholesterol or other lipids

No increase in prolactin levels

No cardiovascular effects

Effective where there is a bipolar element to the condition of schizophrenia

The main advantage is in it providing more choice for the patient and hence more chance of finding satisfactorily low levels of side effects

(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).

Some patients will regard the treatment as unsuitable due to their own genetic predisposition to adverse side effects it causes them and they will prefer another treatment, possibly even typical.

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.

Not familiar

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

I am unaware of any

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.

Not aware

Appendix D – Patient/carer expert statement template

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?

It would provide more choice and therefore more likelihood of finding a tolerable treatment in terms of side effects

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

There would be less choice and therefore less chance of a patient finding a medication to which they were genetically suited such that they experiences tolerable side effects

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

Yes, patients who are not predisposed to it.

Other Issues

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

I am worried that by specifically recommending this drug for an age group those for whom it does not transpire to be suitable because of adverse side effects will lose hope before trying other technologies which may well have been more suitable for them. In addition I feel the possibility of the technology causing sexual side effects for example ejaculatory dysfunction (which are particularly distressing to young people) needs to be made known and open as Aripiprazole is no exception to the rule that sexual dysfunction is a more common side effect of drugs for schizophrenia when compared to non psychoactive drugs.