

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Botulinum toxin type A for the prophylaxis of headaches associated with chronic migraine

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: ELAINE RANSOME

Name of your organisation:

The Migraine Trust

I agree with the organisational statement submitted by The Migraine Trust and am submitting this personal statement in addition.

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)~~

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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.

The technology is able to help with all aspects of the condition, being the head pain and related side effects such as disturbed vision (white spots), nausea and speech difficulties.

Unlike other medicines used to treat chronic migraine (eg Amitriptyline, Nortriptyline etc), there are no side effects with botox

(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.

The benefits are significant, the major one being the reduction of the pain. For me, a reduction from almost constant pain to 2 or 3 days of pain a month.

The reduction in pain has meant that I can regain some normality in my life and not have to spend periods of time in bed in the dark, I have been able to get back to work, spend time with friends, go running etc

Being pain free and able to regain a quality of life has also improved mental health.

It is difficult for employers, friends and family to understand what chronic migraine is, how it works and also how you can appear fine one day but then not the next.

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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).

I do not consider that there is any aspect of chronic migraine that the botox cannot help with.

There are no difficulties in using the botox since it is injected by trained, qualified individuals

There are no side effects associated with the botox

The financial impact is significant, those suffering with chronic migraine are often unable to work, the result being no incoming resources to cover bills, leaving little funds to be able to afford to pay for the treatment, currently the only way to get the treatment.

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

I am not aware of any

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 is only available to those who have been diagnosed as having chronic migraine so obviously those chronic migraine sufferers will benefit more from the technology. People suffering from other types of headache will benefit less from the technology.

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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.

Drugs such as Amitriptyline, Nortryptalin, Pregabalin, Topiramate

(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 tried the majority of the current treatments, all of them providing no benefits and in some cases with unbearable side effects. Therefore the botox showed a massive advantage over the current treatments.

Another advantage is that the botox treatment is much better since it is one treatment every 6 months

(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 don't think there are any disadvantages for patients.

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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 believe that patients' experiences of using the technology reflects those observed under clinical trials

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 not aware 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.

I am not aware of any although I believe there have been trials carried out

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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?

The difference if this technology was available on the NHS would be significant. It would mean that the treatment would be available for all chronic migraine sufferers and also for me personally it would mean that I would be able to have the treatment when required, leaving me pain free and able to have a quality of life

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

If this technology was not made available on the NHS it doesn't even bear thinking about. Botox is the only treatment that took away my constant 13 month migraine. Without it I would be back to experiencing constant pain, not being able to work, spending the majority of my time in bed with my head under a pillow in the dark. I would be left to try yet another drug, unsuccessful in reducing the pain, leaving me in misery and wishing someone would just chop my head off.

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

None that I am aware of

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Other Issues

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

There is a technology which means that a significant number of sufferers can be pain free and regain their life, the absence of funding however, means the majority of sufferers miss out on the opportunity to experience this.