

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: Royal National Institute of Blind People and Macular Disease Society

Are you (tick all that apply):

- 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)

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. Advantages

(a) The technology is expected to dissolve the macular oedema caused by the retinal vein occlusion and as a result improve visual acuity and reduce vision distortion in patients with the condition

(b) Short-term and long-term benefits

The short-term impact on a patient's quality of life will depend on whether there is second eye involvement from retinal vein occlusion or due to other causes.

We have spoken to two patients with macular oedema secondary to central retinal vein occlusion (full case study attached) and both reported that having the condition did not have a major impact on their quality of life because they were treated promptly with dexamethasone and only had to live with reduced visual acuity and some level of distortion in one eye for a limited period of time. Both patients had initially been worried about the idea of having an injection in the eye but were surprised how quick and painfree the procedure was. One of the patients felt some level of discomfort in the 48 hours following the procedure but did not feel that that was a problem.

The short-term benefit of the technology was therefore the ability to continue with their usual day-to-day activities, retaining independence (one of them was a driver), and avoiding reliance on family or friends.

Long-term, the benefits for patients are likely to be magnified since retaining sight in the eye affected by RVO may become a major factor in their quality of life should they develop a condition such as dry age-related macular degeneration (AMD). Since retinal vein occlusions and AMD share some risk factors this is not unlikely. At this point a decision to treat the original retinal vein occlusion will have additional benefits since the patient will not have to rely on successful treatment in his or her remaining eye to prevent blindness.

To illustrate the impact that retinal vein occlusion can have on a person's life please find attached the case study of a woman who lost her sight to central retinal vein occlusion in one eye and developed dry age-related macular degeneration in the other. Since she was unable to receive treatment for her retinal vein occlusion and since she has the dry, untreatable, type of AMD, she is now registered partially sighted and still inexorably progressing towards further sight loss. We are also attaching the case study of an 86 year old man who lost his sight due to retinal vein occlusion nine years ago, developed it also in his second eye and has a number of other eye conditions. Both of them were severely affected by the disease because they had or developed sight problems in the second eye. They are lucky to have the support of sighted spouses without which their situation would be much bleaker.

Practical advantages of the treatment relate to the small number of injections and follow-up visits required when compared with current treatments for age-related macular degeneration. This will certainly have a positive impact since it reduces the need to involve family or friends or request leave from employers.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. Disadvantages

The two patients we spoke to did not see any major disadvantages of having the procedure, primarily because it was quick and pain free but also because the alternative was losing sight in the affected eye.

One patient identified the monitoring regime following the procedure as a disadvantage. However the high number of follow-up visits was due to his participation in a trial and is unlikely to be replicated in clinical practice.

The second patient felt that the only disadvantage was that she had to pay for her treatment privately. She felt very strongly that the treatment should be available on the NHS.

Both agreed that the method of administration was not ideal because most people disliked the idea of having an injection in the eye. However, that paled into insignificance when the consequence of not having the injection was losing sight in one eye.

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

We are not aware of any but have only spoken to a small number of patients.

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?

The treatment does not work differently in different groups of patients. However, patients who receive it early are likely to benefit most since their sight will not have deteriorated as much as in patients who receive the treatment later. Also, comparatively, patients with CRVO will benefit more than those with BRVO because the former do not have effective treatment alternatives.

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.

There are a number of alternative available treatments for macular oedema in BRVO with grid laser photocoagulation the most commonly used in patients whose visual acuity is less than 6/12 for three months. In addition, intravitreal triamcinolone is used in both types of RVO. However, this is not licensed for use in this condition and the manufacturers have stated that it is contra-indicated for use I the eye. Arteriovenous sheathotomy is not widely used.

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

For CRVO the new technology has the advantage of being the only licensed treatment available with clear evidence of its safety and effectiveness. For BRVO the advantage is that patients can receive treatment immediately and do not have to wait for three months to see whether the macular oedema resolves without intervention. Since not all patients experience improvement in their vision it is important to treat as early as possible. This then also leaves the option of rescue laser treatment if necessary.

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them.

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.

No comments.

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

This treatment is not yet being used widely on the NHS.

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.

Deramo et al, 2003: Vision-related quality of life in people with central retinal vein occlusion using the 25-item National Eye Institute Visual Function Questionnaire. Arch Ophthalmol/Vol 121, September 2003.

This article shows the way retinal vein occlusion can impact on a person's quality of life. Although quality of life is most strongly associated with visual acuity in the better seeing eye the study also shows lower scores in a number of areas for patients without second eye involvement.

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?

Patients who cannot afford private treatment will not lose their sight unnecessarily and will therefore be at a lower risk of falls due to decreased depth perception. Their long-term chances of avoiding bilateral blindness will also be increased.

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

This would lead to inequity in access to sight-saving treatment since only patients able to afford treatment would benefit from the new treatment.

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

No

Other Issues

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

We would urge the Committee to consider the loss of utility due to monocular vision but would also like to emphasise the importance of treating monocular eye disease because of the considerable risk of patients developing eye disease in the second eye as they grow older. Apart from the devastating impact of sight loss on the individual, sight loss is also associated with considerable costs to the NHS, Social Services and Society. Robust research commissioned by RNIB in 2009 suggests that this amounts to £2 billion in direct costs and £4 billion in indirect costs and although

Appendix I – Patient/carer organisation statement template

most of this is associated with bilateral vision loss allowing a patient to lose their sight in one eye significantly increases their risk of experiencing partial sight or blindness due to the same or other conditions in the long run.