NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Dexamethasone intravitreal implant for treating diabetic macular oedema [ID653]

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, including health-related quality of life)
- preferences for different treatments and how they are given
- expectations about the risks and benefits of the treatment.

We have already asked your nominating organisation to provide an organisation's view. We are asking you to give your views as an individual whether you are:

- a patient
- a carer (who may be voicing views for a patient who is unable to) or
- somebody who works or volunteers for a patient organisation.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The response area will expand as you type. The length of your response should not normally exceed 10 pages.

1. About you

Your name: Gary Michael Forrest
Name of your nominating organisation: RNIB
Do you know if your nominating organisation has submitted a statement?

X Yes ☐ No

Do you wish to agree with your nominating organisation's statement?

X Yes ☐ No

(We would encourage you to complete this form even if you agree with your nominating organisation's statement.)

Are you:

- a patient with the condition?

X Yes ☐ No

- a carer of a patient with the condition?

☐ Yes X No

- a patient organisation employee or volunteer?
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☐ Yes X No

Do you have experience of the treatment being appraised?

X Yes ☐ No

If you wrote the organisation submission and do not have anything to add, tick here ☐ (If you tick this box, the rest of this form will be deleted after submission.)

2. Living with the condition

What is your experience of living with the condition as a patient or carer?

DMO is the swelling of the Macula. This badly affects your detailed vision and colour rendition.

In my case, pre-Ozurdex, I could not read printed text without the aid of strong magnification, use my computer (work related), colour was practically non-existent, and basic daily activities such as walking around became difficult.

I would often walk into objects, and trip over others easily. On many occasions these would lead to falls where I would graze my legs and knees requiring further cleaning.

Simple things like getting dressed were quite difficult, and making a cup of tea was next to impossible. This lead to accidentally pouring hot water over myself more than once.

I found myself not attempting to do certain tasks such as cooking for fear of more serious accidents.

3. Current practice in treating the condition

Which treatment outcomes are important to you? (That is, what would you like treatment to achieve?) Which of these are most important? If possible, please explain why.

Ease of treatment (application), longevity of positive effects, and no side effects.

This leads to less frequent appointments which allows me to continue working and pursuing some of my hobbies and interests.

It also reduces my reliance on others greatly and allows me to feel more independent.

What is your experience of currently available NHS care and of specific treatments? How acceptable are these treatments – which did you prefer and why?

Previous treatments:

Lucentis works to lesser degree, and does not last very long (the effects wear off after 6 weeks)

Laser retinopathy also works ok, but is painful in application, and has the side effects of scarring.

Ozurdex works very well, almost painless in application, and the effects last a long time. My last Ozurdex injection lasted 14 months.

4. What do you consider to be the advantages of the treatment being appraised?

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

Please list the benefits that you expect to gain from using the treatment being appraised.

Ozurdex positive effects are noticed within days, and last for a long time (over a year in my case), this has really positive effects on life, allowing me to keep my independence, and continuing to work.

Please explain any advantages that you think this treatment has over other NHS treatments in England.

Ozurdex implant is almost painless to administer, the effects last a long time, and would appear to have no negative side effects for me.

Other treatments are either painful, or have side effects (scarring), or only last for a few weeks leading to much more inconvenience.

If you know of any differences in opinion between you and other patients or carers about the benefits of the treatment being appraised, please tell us about them.

I know of no other patients/persons who has had Ozurdex treatment so I am unable to comment.

5. What do you consider to be the disadvantages of the treatment being appraised?

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)
- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)
- any other issues not listed above

Please list any concerns you have about current NHS treatments in England.

Personally there have been no disadvantages for me, Ozurdex has allowed me to continue my life almost without issue, maintaining my independence mostly.

This in turn means I do not have to rely on others as much.

Please list any concerns you have about the treatment being appraised.

None.

If you know of any differences in opinion between you and other patients or carers about the disadvantages of the treatment being appraised, please tell us about them.

None.

6. Patient population

Do you think some patients might benefit more from the treatment than others? If so, please describe them and explain why.

Whilst I do not know any other person who has had Ozurdex, based on my experiences with the treatments available for DMO I would suggest Ozurdex would benefit many people with DMO.

Do you think some patients might benefit less from the treatment than others? If so, please describe them and explain why.

Assuming a person is not susceptible to a steroid adverse reaction, no.

7. Research evidence on patient or carer views of the treatment

Are you familiar with the published research literature for the treatment?

☐ Yes ☒ No

I have read a few articles on the internet, but nothing in depth.

If you answered 'no', please skip the rest of section 7 and move on to section 8.

Please comment on whether your experience of using the treatment as part of routine NHS care reflects the experience of patients in the clinical trials.

Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?

If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?

Are you aware of any relevant research on patient or carer views of the condition or existing treatments?

☐ Yes ☐ No

If yes, please provide references to the relevant studies.

8. Equality

NICE is committed to promoting equality of opportunity and eliminating discrimination. Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, who they are and why.

None.

9. Other issues

Do you consider the treatment to be innovative?

X Yes ☐ No

I consider Ozurdex to be innovative, and very effective.

If yes, please explain what makes it significantly different from other treatments for the condition.

Whilst I have had other treatments for DMO, lucentis (did not last very long) and laser (side effects of scarring), for me Ozurdex made a black and white difference between having useable eye sight and just being able to see shapes/light.

Is there anything else that you would like the Appraisal Committee to consider?

10. Key messages

In no more than 5 bullet points, please summarise the key messages of your submission.

- Ozurdex is quick and almost painless in application.
- Ozurdex's positive effects last a long time, over 1 year.
- Ozurdex allows me to continue an almost normal independent life.
- Which in turn greatly reduces the support I need from friends, family and the NHS.