Executive summary

In total 4548 people responded to the consultation on the draft guidance relating to age-related macular degeneration (AMD). All the letters received were read and the key themes were identified. The main concern of respondents was the impact of deteriorating vision on quality of life, in particular the loss of independence, the impact on daily living and the anxiety and fear of going blind. Respondents considered it illogical and inhumane to treat only the better-seeing eye and described the stress associated with waiting for your sight to deteriorate and the fear that you would ‘miss your chance’ and go blind if treatment did not work. They provided many examples of the considerable difficulties encountered when only one eye is affected. Respondents also challenged the decision to restrict treatment to those with certain types of AMD. They felt that the true costs of blindness (both National Health Service [NHS] and Personal Social Services [PSS] costs and wider societal costs) had been underestimated. Several respondents also reflected on the effectiveness of the treatments they had received for their AMD.

Introduction

This report collates and summarises the public comments on NICE’s draft guidance or Appraisal Consultation Document (ACD) for the appraisal of drugs for AMD.

All emails and letters have been read by NICE, and the collated responses are included in this report. The Institute’s Chief Executive also read a sample of the letters.

NICE would like to acknowledge the time and effort that members of the public put into preparing and sending comments as part of the ACD consultation. Many correspondents also noted how difficult it was to write their letters due to poor eyesight.

Most of the correspondence described patients’ own experiences and families’ personal experiences of having a relative with AMD and expressed concern about the perceived impact of the draft guidance.

Numbers and general overview of comments received
In line with NICE’s published process, the ACD was posted on NICE’s website from 14 June to 12 July 2007. This allowed for the standard 3-week public consultation period as well as an extension of 1 week allowing audio and large print versions of the ACD to be posted on the website.

In total, 4548 people contributed to the consultation on the draft guidance. The analyses of numbers provided in this report are of the 4548 responses (letters, emails, and Braille and tape transcripts). 163 of these comments (4%) were made by respondents from outside the UK. A further 10,000 petitions were received. Comments on the ACD were received in several formats:

a) **Petitions**: Petitions (appendix 1) containing a total of approximately 10,000 signatures from people objecting to the draft guidance were received. These were not included in the analysis for this report.

b) **Letters – personal and standard**: 3552 letters were received, of which 853 (24%) were standard letters (following a template response, see appendix 2) provided by patient organisations with no additional information included. Standard letters were not separated from personal letters; all the issues raised, whether in standard or personal letters, are reflected in this report.

c) **Emails**: 994 emails received before the closing date of the consultation (12 July 2007) were read and included in this report.

d) **Braille and tape comments**: One Braille comment and one tape comment were received. These were transcribed, read and included in the analysis for this report.

4 How NICE dealt with the correspondence

Initially, all letters and emails were read by the NICE Communications team, and correspondents were sent a standard response acknowledging receipt and including more information about the appraisal. If they raised specific questions not covered by the content of the NICE standard letter, a tailored response was sent.

Subsequently, all the correspondence was read and collated by the Patient and Public Involvement Programme and Technology Appraisals team at NICE and they produced this report. Appendix 3 provides a quantitative summary showing the number of respondents who raised each of the issues.

5 Main themes of comments received
From the letters and emails received as part of the ACD consultation it is possible to identify a number of key themes. These are summarised below and outlined in more detail later in the report – along with the addition of selected representative quotes.

- The impact of AMD on patients’ and families’ quality of life.
- Cost considerations.
- Comments on the recommendation to treat only the better-seeing eye.
- Comments on recommendations relating to treatment decisions based on lesion type.
- Comments on the effectiveness of treatments already received.
- Comments relating to equality issues (mainly age of patients with AMD and concerns about unequal access to treatments compared to people living in Scotland and abroad.

6 Exploration of key themes

In correspondence, 705 (16% of the total respondents) people said they disagreed with NICE’s draft recommendations but gave no critique of the issues for the Committee to consider. However, the majority of respondents (3831; 84%) said they disagreed with the recommendations and gave reasons why the Committee should reconsider. The full range of reasons given for disagreeing with the Committee’s recommendations are described below, whether or not they fall within the Committee’s remit. A small number of respondents (12; 0.3%) said that they partially agreed with the draft guidance (for example, that they agreed with the guidance on pegaptanib [Macugen] but not with the guidance on ranibizumab [Lucentis]). No respondent fully agreed with the guidance.

6.1 The impact of AMD on patients’ and families’ quality of life

Respondents stated that deterioration of vision, or blindness, had an impact on their quality of life, and often that of their families, carers or dependants, in a number of ways:

- 1032 respondents (23% of the total) reported loss of independence, (dependence on others, loss of dignity, feeling shame in asking for help), while 1282 (28%) reported an impact on activities of daily living, including, for example, self-care, driving, watching television, reading and other hobbies. Many people reported not just individual areas affected, but a wide range of activities that they or their affected relative could no longer engage in.

“I have had to give up my teaching and my voluntary work. Socialising is problematic. Holidays are now a thing of the past. My garden is now a blur, I can’t see my own face in a mirror. Worst of all is to open my eyes first thing in the morning only to realise that the dark shadows have encroached a little further across my potential field of vision.”
“It is awful to realise there is a treatment available that will halt the deterioration but unavailable unless you say so. If nothing is done, I will be caring for a broken man. Not able to read, to write, to watch television, to use his computer. To have to be escorted everywhere to prevent accidents. To lose independence. To sit in a corner as the sighted world goes by.”

“She loved books and reading was her major pastime – she is lost without this pleasure despite her reading machine and the tapes. She used to drive a car but has had to give it up. She used to travel up to London on tube and bus – with AMD she no longer has the confidence. She has lost her independence.”

“My doctor tells me that I will have to think about residential care as it is not safe to live alone and it will not be possible for me to manage. I would rather be dead.”

- A smaller number of respondents (168; 4%) reported an impact on employment or education.

“I am a writer by profession, and at one point was not able to read the printed page, nor my computer screen, which was a disaster to my career… It was only because I was able to have private treatment that enough sight was restored to one eye to enable me to take up my work once more.”

- 788 respondents (17%) described the psychological impact of loss of vision including fear, anxiety, depression, physical, social and emotional isolation.

“I would like to explain the effect [having the condition in both eyes is] having on her. She is totally preoccupied with this problem, it is on her mind the whole time and she is in a constant state of anxiety and becoming very depressed at the prospect of becoming blind and losing her independence.”

- 462 respondents (10%) identified other quality of life impacts, including increased likelihood, and fear, of falls and accidents, as well as the impact of vision loss on coping with other comorbidities.

“I have also had several trips and falls owing to my inability to see obstructions.”

“I am virtually blind in the left eye and if the right eye goes as well what will I do? I am almost completely deaf in both ears so cannot rely on my hearing either. I told the consultant if he cannot treat me I would beg him to give me an injection and put me out of my misery.”
510 respondents (11%) explicitly mentioned the particular value of sight as one of the most important faculties. 216 (5%) specifically stated in their correspondence that NICE had ignored or underestimated the impact of vision loss/AMD and/or waiting for treatment on patients’ quality of life.

“Mentally, [my mother’s] sight impairment was far more traumatic to her than the fact she had had her leg amputated and was wheelchair bound.”

742 (16%) described the impact that loss of vision had on their family and carers. Comments related both to increased dependence on family and friends, but also the impact that loss of vision had for a person with AMD who might be caring for an elderly relative themselves.

“I am completely reliant upon my daughter in order to be able to go anywhere, do any shopping, or read or answer any of my correspondence.”

“My wife is frail and my sight impairment prevents me from relieving her of various tasks that I otherwise could undertake. It is now evident that my disability will make it necessary to give up our home and independence and look for care facilities sooner rather than much later.”

6.2 Cost considerations

Respondents made a number of different observations about costs, including the cost to the NHS and wider society of not preventing blindness, about whether costs should be taken into account at all, about private versus public funding, about the role of drug companies in setting drug prices and about discrepancies in funding across countries.

6.2.1 NHS and personal social services costs

600 respondents (13% of the total) stated that the cost of the drugs to the NHS and social services would be lower than the future costs of blindness.

“The cost of treatment is a concern but the cost of not treating should also be a concern… In mine and most other cases the ongoing health costs are greater than any false savings on treatment cost. Antidepressant medication for years, ongoing therapy, loss of taxation, additional social benefits and various travel and support benefits are very real costs that do not take into account the holistic obligations and …the pledge of our leadership in NHS for the elderly.”

“The treatment for AMD is absolutely vital for so many people and would also save enormous expense to the Government in health costs having to deal with all the problems which arise i.e. falls, bumps, burns and scalds.”
“To add to my great discomfort I tripped over and had a fall… I sustained a deflected septum in my nose which requires an operation so that I can breathe properly.”

“Surely the injections justify their cost, especially if they work quickly, as in my case, and make lots of visits and procedures at hospital unnecessary.”

“I notice in your guidance you do not factor in the impact of other services when depriving AMD patients of treatment. These include carer support, social services support and the cost to the NHS of prescribing antidepressants since there is evidence that those with AMD are twice as likely to suffer from depression as the general population.”

“Prolonging life with handicap is far more wasteful of resources than is prevention.”

6.2.2 Wider societal costs

• 1044 respondents (23%) queried why NICE didn’t consider the broader societal costs that would be incurred if people went blind unnecessarily.

“My husband is now receiving attendance allowance and if he survives another 20 years, at the minimum rate, that would cost about £40,000. If the victim lives alone…costs to social services would escalate dramatically.”

“Do you and the panel not think that the economic test should take into account what social services costs will be once all AMD sufferers become dependent on social care and other support?”

6.2.3 Costs and access to treatment

• 293 respondents (6%) suggested that costs should not be taken into account at all, with 421 (9%) noting their own contributions to the NHS – for example, as tax payers, NHS employees and war veterans.

“I hope that the committee will consider the further use of ranibizumab on the basis of its clinical performance rather than basing its judgment on the expediency of keeping costs of treatments within the budgets of Primary Care Trusts, something which has little to do with Clinical Excellence.”

• 193 respondents (4%) queried why NICE and the NHS are unwilling to fund treatments that are not self-inflicted when they support the funding of conditions that are.
“I am also annoyed that self-inflicted conditions such as sports injuries and tobacco/drug withdrawal therapies are funded by the NHS but not a hereditary condition such as macular degeneration.”

“The national Lucentis drugs bill would be minute in comparison with the astronomical costs of support for the elderly blind and their dependants. This also seems particularly unfair when our NHS savings are to be squandered on free heroin for jailbirds and nicotine patches for feckless smokers.”

- 177 respondents (4%) commented on the inequity between those who can and cannot afford private treatment. 208 respondents (5%) said they had only been able to access treatment by going private, with several mentioning the considerable drain this had on often limited resources.

“It was only because I was able to have private treatment that enough sight was restored to one eye to enable me to take up work once more. My savings now gone I am reliant on the NHS for any further treatment of this creeping disease.”

“My husband and I are both pensioners…it is not easy to borrow money at our age. We have paid for injections [which have stabilised the sight in my left eye]. But it will go very quickly without maintaining the treatment. The NICE decision has put us in the intolerable situation knowing that this drug will maintain the level of sight I have left in my left eye and then not being able to afford to have it.”

“I have lost the sight in my right eye and am at present having treatment on my left eye. My husband and I have already used up our savings of £8000 on treatment which has stabilised the sight in my left eye.”

- 654 respondents (14%) challenged the fact that NICE was restricting use of treatments when such restrictions did not apply to patients in Scotland or other countries (often commenting that English taxpayers were funding the treatments in Scotland).

6.2.4 Price setting by drug companies

- 21 respondents (0.5%) commented that the drug companies should bring their costs down.

- Some of these respondents highlighted the difference in the cost of Lucentis compared with bevacizumab (Avastin). Some (39; 1%) queried why NICE was not appraising Avastin, and why the manufacturer of Avastin was not seeking a licence for Avastin to treat AMD. Some considered that this should not be outside NICE’s control but that NICE should have a proactive role to play in negotiating these costs.
“It is about time that the drug companies, who make such huge profits, were taken to task for the obscene prices they charge not just in this case but for many other life-enhancing or life-saving treatments, virtually holding the sick and needy to ransom.”

“I accept that the price of Lucentis is ludicrously high given that Aventis can make Avastin for a tenth of the price. I hope that Avastin can be shown to be as effective as Lucentis and bring the cost of therapy down.”

6.3 Comments on recommendation to treat only the better-seeing eye

Respondents disagreed with the decision in the ACD to treat only the better-seeing eye.

- 2550 respondents (56%) stated that treating only the better-seeing eye was wrong, unethical or immoral, or stated that no other dual organs or limbs would be left to collapse without treatment of the first.

“The decision not to treat first eyes is beyond belief and an utterly illogical method of assessment. The human body does have dual organs and limbs, but treatment on one is normally given; we do not wait for the second kidney to fail before treatment of the first, nor do we have to wait for cancer to appear in the second breast before beneficial treatment is given.”

- 217 respondents (5%) stated that first eye blindness is noticeable and does have an impact on patients, and 170 respondents (4%) described the impact of vision loss in one eye, including loss of central and binocular vision, blurring, fogging and wavy lines. People also provided examples of problems encountered when functioning with one eye.

“The loss of sight in my right eye has had the following impact on my life: I experience disorientation due to the imbalance of sight in my eyes. I find it easier to keep my right eye closed (which is an effort in itself), relying solely on my left eye, for most tasks/activities. I can no longer drive as I am unable to judge distances. I am unable to judge the level of the ground in front of me, making me unsteady and nervous of going out alone. My reading is restricted to large print books. Shopping is difficult as I cannot recognise packaging or read contents. I can no longer paint, knit or sew. I do not always see or recognise the faces of people I know. I have to rely heavily on my daughter for help with many tasks e.g. writing this letter.”

“Aged 67, fit, active and independent, I awoke one morning and found my vision distorted. Later that same day at the eye hospital, an indifferent member of staff said, “Well you’ve got AMD – nothing we can do about it, so go home and register with the National Association for the Blind”! Now two years later, I am virtually blind in one eye, this
eye having deteriorated spectacularly from seeing distorted, wiggly lines to a complete grey/black fog.”

“Although so far luckily it has affected only one of my eyes, it has meant a radical change to my life. I can no longer read normal print and have had to give up my research interests. I also no longer drive a car or even sew on a button for myself.”

“Unable to judge distances accurately, you are prone to frequent mishaps – spillages, breakages, tripping up and down steps and on rough ground, leading to medical emergencies like cuts, burns, sprains and back injuries. A confident, well-coordinated person becomes nervous, hesitant, accident prone, dependent on others and consequently very depressed. THIS IS WITH JUST ONE EYE AFFECTED.”

- 18 respondents reported that functioning with one eye did not have an impact on their daily lives.

“I have lost the sight of my right eye through AMD but am still able to cope reasonably well on my own… the prospect of my second eye deteriorating…is frightening.”

- However, some made a case for considering AMD differently from other conditions affecting one eye:

“Many people can and do manage to live with just the one good eye the same as people with one good ear; however, if you have macular problems the situation takes on a whole different aspect. The likelihood is that you will lose your good eye too, making you dependent on others including the state.”

- 147 respondents (3%) voiced concerns that there was no guarantee that the treatment for the second eye would be successful and, if it was unsuccessful, waiting would deny any opportunity to treat the first eye, thereby resulting in total vision loss. Prevention was felt to be more humane and cost effective than having to treat deterioration.

“Surely if both eyes are treated one gets double the chance of saving their sight but if the sight in one eye has gone this halves the chances of keeping sight (i.e. for some people the treatment might not work on the second and might have worked on the first eye)!!”

“In my Mum’s case it was her second eye, although she DID NOT have it in her first eye. It seems ridiculous to wait for the second eye to get wet AMD when you can treat the first. If you do not act on the first eye and a different condition develops in the second eye, the opportunity for treatment on the first eye is lost forever.”
Some respondents were confused about if and how the recommendation on second eye treatment applied to them if sight loss in the first eye was not due to AMD. A number of people were also suffering from conditions such as glaucoma.

“I have had dry AMD for at least 10 years in my right eye, my left eye being deformed since birth and useless. Knowing that in the future I may develop wet AMD, would I qualify for treatment?”

6.4 Comments on recommendations relating to treatment decisions based on lesion type

500 respondents (11%) disagreed with the recommendation to treat based on lesion type, stating that they felt all patients with AMD should be treated regardless of lesion type. Three respondents (0.1%) supported the decision to restrict according to lesion type.

“I do not understand why patients with occult or minimally classic lesions are to be excluded from the potential benefits of this treatment, nor do I understand why treatment will only be available when both eyes are affected.”

“As an academic I am well aware of the importance of evidence-based practice and of the weight that needs to be given to research findings on effectiveness. However, I understand that trial results have shown some level of success with drug treatment using Macugen or Lucentis with people with ALL types of wet AMD (whether classic, minimally classic or occult). I strongly challenge the health economics argument that such treatments should only be offered to the 20% of wet AMD sufferers with classic lesions for whom it is most effective.”

6.5 Comments on the effectiveness of treatments already received

Respondents who have had, or are currently receiving, treatments for AMD shared their experiences of the effectiveness of those treatments.

149 (3%) specifically mentioned that they had experienced improvements from Lucentis:

“I have a diagnosis of wet AMD in my right eye and very poor sight in my left eye. In an effort to avoid blindness in my right eye I have spent almost £5000 for three Lucentis injections at [named hospital]. The treatment has significantly improved my sight and for the moment arrested further deterioration.”

“I am 52 and started losing sight in one eye 18 months ago. I have already lost partial sight in the other eye through optic neuritis. I started treatment 4 months ago [with Lucentis] and have just had the results.
The fluid at the back of my eye has dried up and my vision is no longer distorted.”

- 3 (0.1%) respondents said they had had treatment with Lucentis that had not been effective, although this was partly ascribed to delay in treatment.

- A smaller number (21; 0.5%) reported improvements from having Macugen while 4 (0.1%) said that their treatment with Macugen had proved ineffective.

“When my second eye developed the disease, I received funding for Macugen injections which I continue with, as required, and this is keeping my sight stable…able to use my computer to type this.”

- 293 respondents (6%) reported improvements from drugs other than Lucentis and Macugen – mainly Avastin, but also some positive comments on Photo Dynamic Therapy (PDT) or drugs where the name was not specified.

“After the first [Avastin] injection, my vision was restored, which was miraculous. I then had a second injection a few weeks later. Subsequently I had a Fluorescine Angiography which confirmed the bleeding had stopped and that repair had taken place.”

“I was grateful to receive funding from my PCT for the PDT recommended by my consultant and still have some sight in my first affected eye.”

- 62 respondents (1%) reported that they had had drugs other than Lucentis or Macugen where treatment had not been successful. The majority of these comments related to treatment with PDT, which for some people had not only proved ineffective but had caused greater damage to the eye.

### 6.6 Comments relating to age of patients with AMD

- 189 (4%) of those submitting comments stated that they felt that age was a factor in the ACD decision. The majority of comments perceived that the decision was negatively weighted against the elderly.

“It is impossible not to draw the conclusion that the A in AMD is driving these proposals. They seem to me to be ageist in the extreme and based on some idea that it is not worth spending too much money on those who have not many years to live.”

- Some respondents mentioned the inter-relationship between increasing age and increased comorbidities, which were seen to compound the impact, and their ability to deal with the impact of loss of vision.

“Wet AMD is an extremely debilitating eye condition affecting elderly patients who may be suffering from a variety of other health conditions …[it] often causes a sudden and debilitating loss of vision literally
overnight. Patients do not have time to adjust to this loss of vision which can have serious consequences.”

“Having taken steroids for 30 years, my skin is particularly fragile and tears very easily… Several previous accidents [due to deterioration in sight] have entailed in-hospital treatment for skin grafts, with, of course, substantially added cost.”

- A minority of respondents commented on the impact of the guidance on younger people with AMD. One letter writer also commented on the incremental cost effectiveness ratio (ICER) calculation:

  “I am 34 years old, married with 2 children aged 3 and 6. If you look at drugs on a value for money basis, how much is it going to cost the government, when I go blind, to support me for the rest of my life when I cannot see. How ridiculous is that, 15 minutes [for an injection] every few months, against a lifetime of BLINDNESS?”

  “It would appear, at least with pegaptanib, that the ICER is reduced to a quarter when the time horizon is increased from 3 to 10 years and younger patients would have a prospective horizon of considerably more than 10 years, although it is accepted that the long-term effect of the drug is unknown.”

7 Comments on the content of the consultation document not mentioned elsewhere

- Two individuals and an international women’s group commented on the reference in the ACD to a possible link with smoking:

  “[Our group] is aware that AMD can and does affect otherwise healthy patients who have never smoked. We would therefore reject any suggestion that patients suffering from this condition are necessarily weakened through the ill-effects of smoking. However, a possible link with pollution in the atmosphere might well be a suitable subject for further investigation of the causes of AMD.”

- A handful of correspondents were concerned by the hereditary nature of the condition and the treatment options that would be available to their children and grandchildren, should they develop it.

Patient and Public Involvement Programme and Technology Appraisals Programme, NICE
November 2007

Appendix 1

Petition Examples

Appendix 2

Template style letter Example

Appendix 3
### Summary table of responses per category

<table>
<thead>
<tr>
<th>Categories</th>
<th>Total</th>
<th>As a percentage of overall number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree with recommendations.</td>
<td>4548</td>
<td></td>
</tr>
<tr>
<td>Disagree with recommendations, with no critique of issues.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Disagree with recommendations, with reasons given OR recommendations need to be reconsidered/drugs should be provided.</td>
<td>705</td>
<td>16</td>
</tr>
<tr>
<td>Other, e.g. partially agree with ACD e.g. agree with guidance on pegaptanib (Macugen) but not ranibizumab (Lucentis) or no opinion stated.</td>
<td>3831</td>
<td>84</td>
</tr>
<tr>
<td><strong>Respondent status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondent from outside the UK.</td>
<td>12</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>Impact of deterioration of vision or blindness on quality of life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of independence/impact on social life.</td>
<td>4984</td>
<td></td>
</tr>
<tr>
<td>Impact on activities of daily living/practical considerations, e.g. self care, driving, TV, reading etc.</td>
<td>1032</td>
<td>23</td>
</tr>
<tr>
<td>Impact on employment or education, e.g. I had to give up work because of deterioration of vision/blindness.</td>
<td>1282</td>
<td>28</td>
</tr>
<tr>
<td>Psychological effects e.g. anxiety, depression, fear of blindness, feeling of isolation, lost confidence.</td>
<td>168</td>
<td>4</td>
</tr>
<tr>
<td>Effect/burden on family/carers.</td>
<td>788</td>
<td>17</td>
</tr>
<tr>
<td>Sight is one of the most important things in life/emphasis on the particular value of sight.</td>
<td>742</td>
<td>16</td>
</tr>
<tr>
<td>Other quality of life impacts: accidents due to impaired vision e.g. falls, dizziness etc.</td>
<td>510</td>
<td>11</td>
</tr>
<tr>
<td><strong>Costs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost cutting exercise/rationing/costs shouldn’t be taken into account.</td>
<td>2211</td>
<td></td>
</tr>
<tr>
<td>NHS costs (including PSS paid by NHS) and/or say that this may exceed the cost of the drugs/the costs have been underestimated/failed to consider cost, e.g. NHS costs explicitly stated, broken hip as a result of falling due to impaired vision etc.</td>
<td>293</td>
<td>6</td>
</tr>
<tr>
<td>Non NHS costs (‘societal’, including loss of income, benefits, patient costs of care not covered by NHS, carer costs) and/or say that this may exceed the cost of the drugs.</td>
<td>600</td>
<td>13</td>
</tr>
<tr>
<td>The pharmaceutical companies should reduce the price.</td>
<td>1044</td>
<td>23</td>
</tr>
<tr>
<td>Number of injections - may not need as many treatments so may be cheaper in practice.</td>
<td>21</td>
<td>0.5</td>
</tr>
<tr>
<td>I am self funding treatment and worried that I will not be able to continue paying for my treatment</td>
<td>6</td>
<td>0.1</td>
</tr>
<tr>
<td>NICE should be appraising bevacizumab (Avastin) why is the company not obtaining a licence for bevacizumab (Avastin)</td>
<td>208</td>
<td>5</td>
</tr>
<tr>
<td><strong>Better seeing eye</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treating only the better seeing eye e.g. this is wrong, unethical, immoral or say that no other dual organs or limbs left to collapse without treatment of the first.</td>
<td>3324</td>
<td></td>
</tr>
<tr>
<td>The impact on the patient’s quality of life (e.g. psychological factors such as anxiety, depression etc) has been ignored or underestimated/making people wait for treatment until their vision has deteriorated has a profound effect on their wellbeing.</td>
<td>2550</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>216</td>
<td>5</td>
</tr>
</tbody>
</table>
First eye blindness is noticeable/does have an impact e.g. went to see a specialist when noticing symptoms in only one eye. 217 5
There is no guarantee the better seeing eye will be successfully treated thereby losing the opportunity to treat. 147 3
Positive comments on functioning with one eye. 18 0.4
Negative comments on functioning with one eye. 170 4
Other issues relating to eyes or vision. 6 0.1

**People on treatments** 532
People having treatment effective for them with ranibizumab (Lucentis). 149 3
People having treatment NOT effective for them with ranibizumab (Lucentis). 3 0.1
People having treatment effective for them with pegaptanib (Macugen). 21 0.5
People having treatment NOT effective for them with pegaptanib (Macugen). 4 0.1
People having effective treatment who do not state the name of the drug, state VEG Fs in general, state Bevacizumab (Avastin) or who were treated with PDT e.g. verteporfin for injection (Visudyne) only. 293 6
People having INEFFECTIVE treatment who do not state the name of the drug, state VEG Fs in general, state Bevacizumab (Avastin) or who were treated with PDT e.g. verteporfin for injection (Visudyne) only. 62 1

**Subgroup restriction** 503
Agree with decision to restrict the use of drugs to specific lesion types. 3 0.1
Disagree with decision to restrict the use of drugs to specific lesion types/all patients with wet AMD should be allowed these drugs irrespective of lesion type. 500 11

**Equality** 1037
Scotland, England (or any other country divide). 654 14
Age related. 189 4
Disability discrimination. 6 0.1
Some people can afford private treatment while others cannot. 177 4
Other equality issues. 11 0.2

**Others** 658
Inconsistency with previous NICE PDT guidance. 5 0.1
It is unfair that treatments for blindness are restricted when this is not a "self imposed" illness. 193 4
National Insurance/tax payer/NHS worker for many years. 421 9

**Appendix 4**

**AMD Letters Examples**