

# **NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

## **HEALTH AND SOCIAL CARE DIRECTORATE**

### **QUALITY STANDARD CONSULTATION**

#### **SUMMARY REPORT**

## **1 Quality standard title**

Serious eye disorders.

Date of quality standards advisory committee post-consultation meeting:

01 November 2018.

## **2 Introduction**

The draft quality standard for serious eye disorders was made available on the NICE website for a 4-week public consultation period between 10 September and 8 October 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 20 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

### **3 Questions for consultation**

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?
2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?
3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

4. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

## **4 General comments**

The following is a summary of general (non-statement-specific) comments on the quality standard.

- The statements generally reflect key areas for quality improvement.
- Stakeholders felt there should be more emphasis on:
  - Data collection at national level.
  - Patient empowerment.
  - Dry AMD.
- Concerns were raised about lack of consideration for people with learning disabilities and communication difficulties (such as dementia), as it is felt the statements rely on people self-reporting their symptoms in order to access treatment.
- Widespread availability of equipment and skills in primary care (community optometry) should be considered.
- Stakeholders suggested the 2016 Accessible Information Standard should be referenced in the standard, to enable people with serious eye conditions to access information and manage their care.
- Concerns were raised that the equality impact assessment did not reference people with learning disabilities.

### **Consultation comments on data collection**

- There was a mixed response.
- Stakeholders commented that data collection was possible for all the statements.
- Lack of local infrastructure and systems was highlighted as a potential barrier, as it results in ad hoc data collection, and potentially incomplete data. Stakeholders commented local audit would be required to collect data for statements 1 and 6.
- Local data collection would require modification and reconfiguration of patient administration systems (PAS). A key outcome measure from the National Elective

Care Transformation Programme's Ophthalmology Failsafe Prioritisation was highlighted as a specific example.<sup>1</sup>

- Concerns were raised about outcome data:
  - It is not routinely collected at CGG or provider level.
  - Validity.
  - Data for visual acuity changes would need to be collected manually if an electronic patient record (EPR) system supporting ophthalmology is not used.

### **Consultation comments on resource impact**

- There was a mixed response.
- General concern was raised regarding the need for additional funding and capacity to achieve the statements. Understaffing due to unfilled ophthalmologist posts in hospital eye services was highlighted as a specific issue.
- Stakeholders felt statements 3-6 would be challenging to achieve due to lack of resources available to meet demand in hospital eye services.
- It was suggested that community optometry services could support reducing demand on hospital eye services, highlighting use of OCT as a specific example.
- Greater accuracy of diagnosis, and timely treatment may enable cost savings.

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<sup>1</sup> % Hospital appointments that occur within 25% of their intended follow up period, including rescheduling of hospital initiated cancellations and non-attendance. Source: NHS England (2018) Elective Care High Impact Interventions: ophthalmology specification – draft, p 19.

## **5 Summary of consultation feedback by draft statement**

### **5.1 Draft statement 1**

Adults with cataracts are not refused surgery based on visual acuity alone.

#### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 1:

- Statement:
  - There was general support for this statement.
  - The statement is achievable.
  - Performing cataract surgery based on factors other than visual acuity is important for enabling more equitable access to surgery, and improving outcomes.
  - Concern was raised about restrictions on second-eye surgery. It was suggested that the statement and quality measures are reworded to convey that they apply to first and second eyes which have a cataract.
  - Some optometrists are having to implement restrictions by not referring patients for second eye surgery because their visual acuity is considered too good following surgery to the first eye. It was suggested that the rationale should be amended to acknowledge this issue.
- Structure measures:
  - A concern was raised that the quality measure may result in CCGs imposing stricter criteria to manage demand.
  - Adopting a more holistic approach to assessment at the point of referral may require additional training for optometrists. It was felt that GPs lack the expertise and capacity to deliver such assessments.
  - Recording a pre-referral discussion has taken place does not demonstrate the relevant topics were discussed.
- Process measures:

- The measure does not include adults who are managed in primary care because their cataract does not require surgery; the denominator should include adults with significant or operable cataract.
- Some adults may, despite meeting referral criteria, be dissuaded from undergoing surgery once referred into secondary care.
- It was suggested that people who are involved in the pre-referral discussion are specified in the definition.

### **Question 2 – data collection**

- Data relating to conversion rates for referrals to surgery would need to be collected locally.
- A concern was raised that it could be challenging to collect data from optical practices who do not provide extended primary care services.

### **Question 3 – resource impact**

- Stakeholders raised concerns that widening referral criteria could increase demand, commenting specifically on a shortage of ophthalmology training posts in relation to capacity.
- Restriction of access to second-eye surgery is used as a strategy to manage current high levels of demand.
- Generating efficiencies and creating sustainable services were highlighted as ways of meeting demand in the context of under resourcing.

## **5.2 Draft statement 2**

Adults have case-finding tests in primary care before referral for further investigation and diagnosis of chronic open angle glaucoma (COAG) and related conditions.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 2:

- There was support for this statement.
- Pre-referral case-finding supports improved access to treatment, helping to avoid vision loss.
- The statement is achievable.
- A concern was raised that using the term 'primary care' could be misinterpreted to mean that GPs perform case-finding tests; 'community optometry' was suggested as an alternative.
- Query regarding whether case-finding occurs during a routine consultation.
- Stakeholders suggested references to reducing anxiety should be removed throughout the statement.
- Structure measures:
  - The equipment required for case-finding tests is widely available and optometrists have the required core (and sometimes advanced) levels of competency to perform the tests.
  - Stakeholders suggested evidence of service level agreements with retail optometrists is added. Service specifications were highlighted as a relevant data source.
- Process measures:
  - a) Stakeholders felt that the measure lacked clarity and does not convey that the quality of referrals from primary care is being measured.
- Outcomes:
  - b) Specifying a patient or a carer survey is inadequate; both should be cited as the data source.
  - b) Satisfaction can be subjective.

## **Question 2 – data collection**

- Query whether service agreements for retail optometrists support providing data required by the quality measures.
- A concern was raised that if primary and secondary care providers do not align definitions of COAG and related conditions some referrals from primary care may be recorded, incorrectly, as false positives.



### **5.3 Draft statement 3**

Adults with late age-related macular degeneration (AMD) (wet active) start treatment within 14 days of referral to the macular service.

#### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 3:

- There was support for this statement.
- Stakeholders raised concerns about the use of unlicensed medicines, suggesting additional information is included in the statement to highlight the issues surrounding this.
- It was suggested that outcome a) also measures gain of vision.
- It was suggested that the audience descriptors include a reference to service providers obtaining and documenting informed consent for treatment using unlicensed medicines.

#### **Question 2 – data collection**

- Stakeholders commented that the statement should be straightforward to monitor.
- Concerns were raised about the quality of data collected for measures, which stakeholders linked to a lack of systematic audit for wet AMD.

#### **Question 3 – resource impact**

- The statement may be challenging to achieve as hospital eye services lack resources and capacity to meet current demand. Potential impact on treating other serious eye conditions that are treated using injections was highlighted as a specific concern.

## **5.4 Draft statement 4**

Adults with late age-related macular degeneration (AMD) (wet active) have ongoing monitoring for both eyes.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 4:

- There was support for this statement.
- The statement should be broadened to include treatment.
- A concern was raised that the statement wording did not emphasise the importance of having appointments at clinically appropriate intervals, and it was suggested that the interval is defined.
- Process measures:
  - Stakeholders suggested that monitoring appointments could be delivered in optical practices to help reduce pressure on hospital eye services.
- Stakeholders suggested including a key outcome measure from the National Elective Care Transformation Programme's Ophthalmology Failsafe Prioritisation as an outcome.<sup>2</sup>

### **Question 2 – data collection**

- Lack of systematic audit, and EPR presents a potential barrier in some trusts.
- The impact of local data collection on data consistency was raised as a concern. It was suggested that where possible, appropriate measures should be introduced into the National Ophthalmology Audit Database.

### **Question 3 – resource impact**

- Concerns were raised that the statement may be challenging to achieve as hospital eye services lack the resources to meet current demand.

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<sup>2</sup> % Hospital appointments that occur within 25% of their intended follow up period, including rescheduling of hospital initiated cancellations and non-attendance. Source: NHS England (2018) Elective Care High Impact Interventions: ophthalmology specification – draft, p 19.

## **5.5 Draft statement 5**

Adults with chronic open angle glaucoma (COAG) and related conditions have reassessment at specific intervals.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 5:

- There was support for this statement.
  - Include delay targets from the National Elective Care Transformation Programme.<sup>3</sup>
- Process measures:
  - The measures are consistent with recommendations in NICE's guideline on [glaucoma](#). It was also suggested that the measures reference the intervals determined by the risk of progression.
- Outcomes:
  - b) should reference specific examples of tools to obtain more meaningful patient feedback.

### **Question 2 – data collection**

- Stakeholders felt monitoring performance would be straightforward.

### **Question 3 – resource impact**

- Concerns were raised that the statement may be challenging to achieve as hospital eye services lack the resources to meet current demand.

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<sup>3</sup> NHS England (2018) Elective Care High Impact Interventions: ophthalmology specification – draft, p 19.

## **5.6      *Draft statement 6***

Adults with age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are given a certificate of vision impairment (CVI) as soon as they are eligible.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 6:

- There was general support for this statement.
- It was highlighted that achieving the statement could rely on the efficiency and quality of the contributions of individual staff members.
- The statement does not emphasise that the process of offering certification is more important than giving the certificate to a person with COAG or AMD; the offer may be declined initially but taken up later.
- Variation in approaches to managing the certification process was raised as a concern. It was highlighted that achieving the statement could rely on the efficiency and quality of the contributions of individual staff members.
- The statement should refer to other serious eye conditions, with dry AMD highlighted as a specific example.
- A query regarding whether ophthalmologists must always be involved in the certification process, and if not, whether a more holistic assessment is possible.
- Structure measure:
  - COAG needs to be included.
  - The measure should refer to the certificate and supporting information being available in the person's preferred format, and meeting the Accessible Information Standard.
  - It was suggested that the measure should mention that ideally, an ECLO (eye clinic liaison officer) would support the certification process.
- Process measures:

- Stakeholders felt the measures do not capture whether the CVI was offered at the right time, and it was highlighted the denominator is those who are eligible for a CVI.

### **Question 2 – data collection**

- Local audit would be required.
- The efficiency of individual local eye clinics could affect the recording and monitoring of data; issues with recording and monitoring data may correlate with units where barriers may exist. Specific examples of these were highlighted:
  - External pressure to keep certification rates low.
  - Lack of awareness that certification offers a route to services at the point of eligibility.
  - Incorrect assumptions about a person’s need for certification.
  - The current version of the CVI form has questions about applicants’ additional needs (for example, learning disabilities or dementia); this would support the collection of data relating to equalities.

### **Question 3 – resource impact**

- Concerns were raised that the statement may be challenging to achieve as hospital eye services lack the resources to meet current demand.

## 6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Other serious eye disorders should be included:
  - Diabetic retinopathy (assessment and management).
  - Retinitis pigmentosa.
- Improving data collection relating to wet AMD, which could enable adults with wet AMD and their carers evaluate AMD services.
- A separate statement to support implementation of the Accessible Information Standard to facilitate improved access to eye services, adherence to treatment, and help people manage their eye condition.
- Access to minimally invasive glaucoma surgery (MIGS).
- Stakeholders suggested a statement about provision of ECLOs should be included, to recognise their role in providing information and access to a range of services (habilitation, rehabilitation, advice and support), and recognise variation in current provision.

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## Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments <sup>4</sup>
1	Alliance Pharma PLC	General comment	We have no comments to add at this stage to the proposed content, but we appreciate being a stakeholders and being invited to comment at the next stages.
2	Newmedica	General comment	Newmedica would like to formally support this quality standard. We have no further comments
3	Optical Confederation	General comment	We are disappointed that there has not been greater effort to include quality standards that more fully consider or appreciate properly take account of the prevalence of appropriate equipment and skills in primary care environments.
4	Royal College of Nursing	General comment	Nurses caring for people with Serious eye disorders were invited to review the draft quality standard and there are no further comments to make on this document on behalf of the Royal College of Nursing.
5	Royal National Institute of Blind People (RNIB) with the support of Vision UK	General comment – proposed statement 7	<p>RNIB is calling for inclusion of a quality standard about implementation of the Accessible Information Standard (known as DCB1605).</p> <p>The Accessible Information Standard was introduced in England in August 2016 after many years of campaigning from charities including RNIB, Action on Hearing Loss, Sense and Mencap. RNIB research in 2015 found that 86% of blind and partially sighted people found it difficult or impossible to read medication information.</p> <p>Recent feedback to RNIB from campaigners and members of RNIB’s Connect community suggests that, despite the introduction of the Accessible Information Standard DCB 1605, there are still large numbers of blind and partially sighted people who are not receiving information and appointment letters from health services in a format they can access.</p> <p>Including a NICE quality standard about implementation of DCB1605 will help ensure eye care services implement this vital standard. This will help ensure blind and partially sighted people are able to access eye care services, adhere to treatment regimens and manage their eye conditions.</p>

<sup>4</sup>PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments <sup>4</sup>
6	Royal National Institute of Blind People (RNIB) with the support of Vision UK	General comment – proposed statement 8	<p>RNIB is calling for inclusion of a standard about the provision of Eye Clinic Liaison Officers (ELCOs) to provide patients with information and access to habilitation, rehabilitation, advice and emotional support services. Currently 44% of the largest 150 eye departments in England do not have access to an accredited ECLO service.</p> <p>Evidence on the effectiveness of ELCO services has been accepted for publication in the BMJ Open, in an article entitled “The impact of sight loss advisors in clinics: a qualitative study of UK ophthalmology outpatient departments” will be published in the near future.</p>
7	SeeAbility	General	<p>The standard tends to rely on patients to self report and this is not always going to be the case for patients with learning disabilities. Please can this be highlighted, as it will also be an issue for those with dementia and other communication difficulties. Unfortunately we see too many people, often with their whole lives ahead of them in their 20s or 30s, who are struggling to get the surgery or treatment they need because of their learning disability. As time goes on and delays occur this has led to the greater difficulties in operation due to the dense nature of the cataract or complications serious eye disorders.</p>
8	SeeAbility	p. 24 [Equality, diversity and language section]	<p>Disappointing to see no mention of the Accessible Information Standard for the NHS which should ensure that people get information in the format required. This should accompany the statement on equality and language.</p> <p>Please reference the NHS Accessible Information Standard which all NHS and care organisations are legally obliged to follow: <a href="https://www.england.nhs.uk/ourwork/accessibleinfo/">https://www.england.nhs.uk/ourwork/accessibleinfo/</a></p> <p>Please in highlighting the publication of the quality standard could you report that SeeAbility can support the Accessible Information Standard as we have information we publish in easy read on different eye conditions and surgery. See <a href="http://www.seeability.org/looking-after-your-eyes">www.seeability.org/looking after your eyes</a>. This includes information on preparing for eye surgery including an Easy Read Eye Surgery Support Plan, which has been endorsed by Moorfields Eye Hospital.</p>
9	University Hospitals Bristol NHS Foundation Trust	General Comment	<p>No comment on the quality standard.</p>
10	Novartis Pharmaceuticals UK Ltd	Question 1	<p>The draft NICE quality standard for serious eye disorders reflects many of the priority areas for improvement in serious eye disease. Novartis in particular welcome the focus on the following increasing prompt referrals, improving appropriate treatment, and supporting consistent monitoring and follow-up in statements 3, 4 and 6.</p> <p>However, there remain a number of areas which have not received due attention, or have been omitted more broadly, including: the assessment of diabetic retinopathy as a serious eye disease, the collection of data at a national level, patient empowerment and a recognition of the importance of follow-up treatment [...]</p> <p><u>Diabetic retinopathy</u></p>



ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>We are concerned that no recommendations relating to diabetic retinopathy were included in this draft quality standard. Diabetic retinopathy remains one of the leading causes of blindness among people of working age,(14) and is a common consequence of diabetes. One study has found that within 20 years of diagnosis nearly all people with type 1 diabetes, and two thirds of those with type 2, have some degree of retinopathy.(15) As diabetes affects approximately four million people in the UK currently living with the disease and is predicted to rise in coming years, diabetic retinopathy is likely to also increase as a result.</p> <p>The UK diabetic retinopathy screening programme has had considerable success in identifying people at risk and NICE approved treatments exist for people diagnosed with diabetic macular oedema. Nevertheless, outcomes will only be improved if patients are able to access all the treatment and the follow-up that they need in a timely fashion. Given not least the considerable pressure under which NHS retina services in particular find themselves, NICE quality standards in this area should make an important contribution to ensuring that patients with this form of serious eye disease are appropriately prioritised and cared for.</p> <p>As a result, the current absence of NICE standards relating to diabetic retinopathy is a serious omission and efforts to treat this disease must be presented in future NICE standards.</p>
11	The Industry Vision Group	Question 1	<p>The draft NICE quality standard for serious eye disorders reflects many of the priority areas for improvement in serious eye disease. The Industry Vision Group (IVG) has welcomed the focus on the following: increasing prompt referrals, improving appropriate treatment, and supporting consistent monitoring and follow-up.</p> <p>However, there remain a number of areas which have not received due attention, or have been omitted more broadly, including: the assessment of diabetic retinopathy as a serious eye disease, the collection of data at a national level, patient empowerment and a recognition of the importance of follow-up treatment [...]</p> <p><u>Diabetic retinopathy</u></p> <p>We are concerned that no recommendations relating to diabetic retinopathy were included in this draft quality standard. Diabetic retinopathy remains one of the leading causes of blindness among people of working age,(16) and is a common consequence of diabetes. One study has found that within 20 years of diagnosis nearly all people with type 1 diabetes, and two thirds of those with type 2, have some degree of retinopathy.(17) As diabetes affects approximately four million people in the UK currently living with the disease and is predicted to rise in coming years, diabetic retinopathy is likely to also increase as a result.</p> <p>The UK diabetic retinopathy screening programme has had considerable success in identifying people at risk and</p>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>NICE approved treatments exist for people diagnosed with diabetic macular oedema. Nevertheless, outcomes will only be improved if patients are able to access all the treatment and the follow-up that they need in a timely fashion. Given not least the considerable pressure under which NHS retina services in particular find themselves, NICE quality standards in this area should make an important contribution to ensuring that patients with this form of serious eye disease are appropriately prioritised and cared for.</p> <p>As a result, the current absence of NICE standards relating to diabetic retinopathy is a serious omission and efforts to treat this disease must be presented in future NICE standards.</p>
12	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Question 1	It reflects the key areas for quality improvement. Adoption of the suggestions above will ensure the quality standards more accurately reflect these key areas.
13	Thomas Pocklington Trust	Question 1	<p>We are uncertain if the draft quality standard covers the main areas for improvement. We would welcome a note within the guidance, given that it is entitled 'serious eye disorders', about Diabetic Retinopathy and also Retinitis Pigmentosa (RP).</p> <p>It is estimated that 1,360,350 people in the UK will be living with Diabetic Retinopathy by 2025. People with Diabetes can reduce the risk of developing Diabetic Retinopathy, or stop it from getting worse, by closely managing their Diabetes, making recommended lifestyle changes and getting regular retinal screening. Where Diabetic Retinopathy does occur, sight loss can be prevented if it is detected and treated early enough. There is a note about Diabetic Retinopathy within NICE guideline [NG28] Type 2 diabetes in adults: management, however more detailed guidance around diagnosis, treatment and management of the condition should exist.</p> <p>Retinitis Pigmentosa (RP) is estimated to affect 25,000 people in the UK. Although there is currently no known cure or treatment, it is a progressive condition that requires ongoing monitoring. People with RP need practical and emotional support at various times throughout their lives, not just after initial diagnosis. There is currently no NICE guideline or pathway on the diagnosis, management and treatment of Retinitis Pigmentosa.</p>
14	Novartis Pharmaceuticals UK Ltd	Question 2	<p>Data collection for the specific quality measures should be possible, however there remain considerable challenges within ophthalmology related to the collection of outcomes data.</p> <p>Across ophthalmology, there is still a lack of robust data related to outcomes as it is not routinely collected at a CCG or provider level.(16) This makes assessing poor performance and learning from best practice challenging.(17) An enhanced approach to data collection, with due regard to access to treatment, follow-up, outcomes and specific indications must be adopted as it is essential to permitting the monitoring of improved outcomes on a local and</p>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>national level.</p> <p>Specifically for this draft quality standard, relevant data must be published so that records can be accurately assessed and commissioners and providers held to account on performance.</p>
15	Optical Confederation	[Question 2]	There is a lack of local infrastructure and systems to enable the requested data gathering. Unless these systems are put in place there is a significant risk that data gathering will remain disjointed and ad hoc and the resulting data will present an incomplete picture.
16	SeeAbility	[Question 2]	<p>There is no mention of the need for data to be more robust in terms of assessing impact on different groups of the Quality Standard. We know data collection is very poor around equalities and for people with learning disabilities accessing eye care and hospital services so reasonable adjustments can be made</p> <p><a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12244">https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12244</a></p> <p>...</p>
17	The Industry Vision Group	Question 2	<p>Data collection for the specific quality measures should be possible, however there remain considerable challenges within ophthalmology related to the collection of outcomes data.</p> <p>Across ophthalmology, there is still a lack of robust data related to outcomes as it is not routinely collected at a CCG or provider level.(18) This makes assessing poor performance and learning from best practice challenging.(19) An enhanced approach to data collection, with due regard to access to treatment, follow-up, outcomes and specific indications must be adopted as it is essential to permitting the monitoring of improved outcomes on a local and national level.</p> <p>Specifically for this draft quality standard, relevant data must be published so that records can be accurately assessed and commissioners and providers held to account on performance.</p>
18	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Question 2	All indicators are possible to collect but do require local work in trusts and between trusts and commissioners to produce. For instance, the delay in follow ups (25%) may need some adaptation of trust PAS IT systems to generate a report but is possible. Proportions of eligible patients offered CVI would need local trust audit as will conversion rate for cataract referrals. Number of letters visual acuity loss and gain is straightforward to measure if units have an ophthalmic specific EPR but without that requires manual audit.
19	Novartis Pharmaceuticals UK Ltd	Question 3	<p>In order for this quality standard to be delivered, there has to be sufficient improvements to relieve current pressures within ophthalmology services, as evidenced in the declining performance of Sustainability and Transformation Partnerships (STPs) in England against the 18-week referral to treatment (RTT) target:</p> <ul style="list-style-type: none"> <li>• Between January 2017 and 2018, the number of STPs meeting the 18 week referral target for ophthalmology</li> </ul>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>dropped by 50%, from 22 to 11(18). In the same time-frame, only seven out of 44 STPs met the 18-week RTT target for ophthalmology every month.(19)</p> <p>Delivery against the quality standard will require additional funding, but will also mandate non-financial levers, out of the scope of the quality standard.</p> <p>The ophthalmology workforce is also under significant strain, with more needing to be done to relieve the current burden placed on secondary care.(20) According to the Royal College of Ophthalmologist's most recent Workforce Census Report, approximately half of the secondary care units surveyed have unfilled consultant positions, with over 90% undertaking waiting list initiative surgery or clinics. (21) Expanding the number of primary care optometrists within the eye care treatment pathway can relieve pressure on secondary care services through admitting patients earlier in the treatment pathway at a stage of limited progression of the disease. Linked to this, greater use of community OCT use has the potential to improve care.</p> <p>Follow-up treatment as well as ongoing monitoring should be incentivised through changes to the tariff system, to ensure that financial incentives do not undermine clinical priorities. At present, the system prioritises new patient activity over follow-ups through the concentration on the RTT 18-week target for new patients and a lack of similar target for follow ups, and the front loading of the new patient tariff by 30% versus the follow up tariff.(22) The tariff system must be adapted to support all patients at all stages of disease progression, not just diagnosis.</p> <p>With regards to potential cost savings, improvements to the ophthalmology services, in particular for accurate diagnosis and swift treatment, could significantly reduce the financial implications of poor eye health. One key example is the annual cost of falls attributed to those with visual impairment, which constitutes £56.5 million and accounts for 21% of the total medical cost of falls.(23)</p>
20	The Industry Vision Group	Question 3	<p>In order for this quality standard to be delivered, there has to be sufficient improvements to relieve current pressures within ophthalmology services, as evidenced in the declining performance of Sustainability and Transformation Partnerships (STPs) in England against the 18-week referral to treatment (RTT) target:</p> <ul style="list-style-type: none"> <li>• Between January 2017 and 2018, the number of STPs meeting the 18-week referral target for ophthalmology dropped by 50%, from 22 to 11.(20) In the same time-frame, only seven out of 44 STPs met the 18-week RTT target for ophthalmology every month. (21)</li> </ul> <p>Delivery against the quality standard will require additional funding, but will also mandate non-financial levers, out of the scope of the quality standard.</p> <p>The ophthalmology workforce is also under significant strain, with more needing to be done to relieve the current</p>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>burden placed on secondary care.(22) According to the Royal College of Ophthalmologist's most recent Workforce Census Report, approximately half of the secondary care units surveyed have unfilled consultant positions, with over 90% undertaking waiting list initiative surgery or clinics.(23) Expanding the number of primary care optometrists within the eye care treatment pathway can relieve pressure on secondary care services through admitting patients earlier in the treatment pathway at a stage of limited progression of the disease.</p> <p>Follow-up treatment as well as ongoing monitoring should be incentivised through changes to the tariff system, to ensure that financial incentives do not undermine clinical priorities. At present, the system prioritises new patient activity over follow-ups through the concentration on the RTT 18-week target for new patients and a lack of similar target for follow ups, and the front loading of the new patient tariff by 30% versus the follow up tariff.(24) The tariff system must be adapted to support all patients at all stages of disease progression, not just diagnosis.</p> <p>With regards to potential cost savings, improvements to ophthalmology services, in particular for accurate diagnosis and swift treatment, could significantly reduce the financial implications of poor eye health. One key example is the annual cost of falls attributed to those with visual impairment, which constitutes £56.5 million and accounts for 21% of the total medical cost of falls.(25)</p>
21	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Question 3	<p>Statements 3-6 are going to be challenging to meet. This is because the whole hospital eye service is over stretched and under-resourced. However, this is even more reason to set reasonable quality standards to measure to demonstrate more funding may be needed for patient safety.</p> <p>The other statements are achievable currently.</p>
22	Novartis Pharmaceuticals UK Ltd	Question 4	N/A
23	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Question 4	<p>There are examples in the RCOphth document <a href="#">The Way Forward</a> and available via the NHS National Elective Care Transformation programme Ophthalmology High Impact Intervention and Ophthalmology Failsafe Prioritisation <a href="https://future.nhs.uk/connect.ti/ECDC/view?objectId=12183216&amp;exp=e1">https://future.nhs.uk/connect.ti/ECDC/view?objectId=12183216&amp;exp=e1</a> Elective care community of practice. Ophthalmology Failsafe Prioritisation. Access can be granted to relevant NHS applicants by application to England.electivecare@nhs.net There are also quite a number of publications in the literature of innovative pathways to achieve the standards e.g. the Huntingdon and Bristol and similar cataract and glaucoma shared community schemes and a few examples are cited here but there are more:</p> <ol style="list-style-type: none"> <li data-bbox="779 1193 2159 1281">1. Ratnarajan G, Newsom W, Vernon SA, et al. The effectiveness of schemes that refine referrals between primary and secondary care—the UK experience with glaucoma referrals: the Health Innovation &amp; Education Cluster (HIEC) Glaucoma Pathways Project. <i>BMJ Open</i> 2013;3: e002715. doi: 10.1136/bmjopen-2013-002715</li> <li data-bbox="779 1281 2159 1340">2. Shared care of patients with ocular hypertension in the Community and Hospital Allied Network Glaucoma Evaluation Scheme (CHANGES). A Mandalos, R Bourne, K French, W Newsom, and L Chang. <i>Eye</i> . 2012 Apr;</li> </ol>

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			<p>26(4): 564–567.</p> <p>3. Gray SF, Spry PGD, Brookes ST, et al. The Bristol shared care glaucoma study: outcome at follow up at 2 years. <i>British Journal of Ophthalmology</i> 2000; 84:456-463.</p> <p>4. C Park, J &amp; Ross, AH &amp; Tole, Derek &amp; Sparrow, John &amp; Penny, J &amp; V Mundasad, M. (2008). Evaluation of a new cataract surgery referral pathway. <i>Eye</i>. 23. 309-13.</p> <p>5. LOCSU <a href="http://www.locsu.co.uk/community-services-pathways/">http://www.locsu.co.uk/community-services-pathways/</a></p>
24	SeeAbility	Equality impact assessment [EIA]	<p>Disappointing to see no mention of people with learning disabilities in the EIA, given their known higher risk of serious sight problems, only a mention of older people. Please can this be rectified especially as both NICE guidelines on cataract and on glaucoma have noted the needs of people with learning disabilities and prevalence.</p> <p>Adults with learning disabilities are 10 times more likely to have serious sight problems than the general population (see research commissioned by RNIB and SeeAbility <a href="http://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities">http://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities</a>). Cataracts are one of the most common reversible causes of visual loss in patients with a learning disability (for example see: <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1857461/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1857461/</a>)</p> <p><b>Approach and reasonable adjustments</b></p> <p>The Management of Visual Problems in adult patients who have learning disabilities is also the subject of a Royal College of Ophthalmologist guideline. See: <a href="https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2011_PROF_128_The-management-of-visual-problems-in-people-with-learning-disabilities.pdf">https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2011_PROF_128_The-management-of-visual-problems-in-people-with-learning-disabilities.pdf</a></p> <p>The following research advocates a multidisciplinary approach and early support planning to achieve outcomes for these patients - see <a href="http://www.magonlinelibrary.com/doi/abs/10.12968/ijop.2014.5.6.212">http://www.magonlinelibrary.com/doi/abs/10.12968/ijop.2014.5.6.212</a></p>
<b>Statement 1</b>			
25	Alcon Eye Care UK Ltd	Statement	We welcome the overall approach being taken by the quality standard committee in relation to these quality standards. We are pleased with the recommendation that there should be no visual acuity thresholds for referral for cataract surgery. This is an important and progressive step that will mean better outcomes for patients in the NHS and we encourage STPs and affiliated CCGs to review and implement these quality standards to ensure patients have access to effective cataract treatment
26	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Statement	RNIB supports this quality statement but would like it to include a reference to second eye as outlined in NG77 1.6.2, which would amend the wording to “Adults with cataracts are not refused surgery in first or second eye based on visual acuity alone.”
27	Royal National Institute of Blind People (RNIB) with	Rationale	A recent press freedom of information request to CCGs revealed that access to surgery is being restricted by imposing arbitrary visual acuity thresholds. RNIB has concerns that some optometrists are having to implement

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	the support of Vision UK		<p>these restrictions by not referring patients for second eye surgery because their visual acuity is deemed 'too good' following surgery to the first eye, despite the impact that this decision may have on the patient's life and independence.</p> <p>Amend the wording of the final sentence of the rationale to: "Restricting access to surgery based on visual acuity in the affected eye alone has an impact on quality of life for some people with cataracts."</p>
28	NHS England (Primary care)	Measure	<p>Overall cannot fault the areas and the aspiration to look at cataract surgery after more of a holistic assessment. Additional training in this assessment may be required and presumably this will be at the point of referral (usually optometrists, I doubt GP's have the capacity or expertise).</p> <p>The recording of this discussion happening doesn't necessary reflect the degree that it was discussed.</p>
29	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Structure measures	<p>Change wording to "Evidence of local agreements detailing criteria, which are not based on visual acuity alone, to be used for referrals and access to cataract surgery in both first and second eyes."</p>
30	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure 1a	<p>The denominator should be amended to 'the number of adults who are referred for cataract surgery'. This is because only those patients with visually significant cataract will be referred to see the ophthalmologist. Many people have a small bit of cataract and do not have any problems at all and are successfully managed in primary care without surgery. Doctors will have a discussion with those who may benefit from surgery.</p>
31	Optical Confederation	Process measure 1b	<p>In areas without defined extended primary care services, it will be hard to measure the number of patients who are referred as the data gathering will be scattered. In areas with commissioned services this will be far easier to measure and quality check. There is therefore a real possibility that the total number of patients with cataract will be nothing more than a rough estimate, unless all optical practices are suitably engaged in data collection.</p>
32	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure 1b	<p>The denominator will be impossible to measure, as many patients have a small bit of cataract which causes them no problems. They are successfully managed in primary care without being referred for surgery. This standard will give no indication as to the quality of care, as there is no need to refer people who have cataracts unless they are having visual problems. We therefore feel this standard should be deleted.</p>
33	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure 1c	<p>The quality measure should be amended to 'Proportion of patients with significant/operable cataract refused surgery based on visual acuity alone.'</p> <p>Numerator should be 'the number in the denominator for which surgery is refused based on visual acuity alone.'</p> <p>Denominator should be 'the number of adults with significant/operable cataract who have cataract surgery performed.'</p>
34	Optical Confederation	Process	<p>This statement may be hard to measure as we hear anecdotal evidence from patients that they are currently</p>

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		measures 1c and 1d	dissuaded from cataract surgery by consultants despite meeting both Visual Acuity and other considerations such as glare. It will be very hard to separate these to obtain any meaningful measure.
35	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure 1d	The quality measure should be 'Proportion of referrals for cataract surgery who do not undergo cataract surgery (ie conversion rate).'
36	Royal National Institute of Blind People (RNIB) with the support of Vision UK	New process measure, 1e	Proportion of adults with significant, operable cataracts in both eyes who have had cataract surgery on both eyes Numerator – the number in the denominator who have undergone cataract surgery in both eyes Denominator – the number of adults with significant, operable cataracts in both eyes
37	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Definitions	The heading 'Based on visual acuity alone' follows a list of different audiences but refers to a 'discussion' but doesn't say who is involved in the discussion.
38	The Industry Vision Group	Question 1	This quality statement tackles basing cataract surgery on visual acuity alone, which is a considerable concern within ophthalmology and can restrict early patient access to treatment, in turn affecting patient outcomes. There have been multiple reports of rationing of cataract services on the basis on arbitrary visual acuity thresholds to save costs, despite NICE guidelines outlining that this is neither good practice nor cost-effective to the NHS.(1)  The IVG welcomes this clarification which is essential for ensuring equitable patient access to cataract surgery across the country.
39	Thomas Pocklington Trust	Question 3	We welcome the decision to widen the criteria for referral, however resources must meet the increased demand that this will create. Evidence suggests that hospital eye services are not able to keep pace with the current level of demand for cataract surgery. Various CCGs have attempted to alleviate demand by restricting access to second eye cataract surgery, however this is not an appropriate solution. More ophthalmologists are urgently needed, yet appeals from the Royal College of Ophthalmologists (RCOphth) to increase the number of UK ophthalmic training posts have been declined.  'The Way Forward - Cataract' is a resource from the RCOphth that presents options to improve efficiency and create services that are sustainable in the face of such growing disparity between demand and resource.  We are concerned that 'local agreements detailing criteria' will result in some CCGs imposing stricter criteria to manage demand, creating a 'postcode lottery'. There should be clear national guidance to support local decision making and facilitate equal access to cataract surgery across the UK.
<b>Statement 2</b>			
40	NHS England (Primary Care)	[Statement]	This probably pertains more to optometry who should be able to refer direct to ophthalmology for suspected COAG and not go via the GP. Presumably case-finding with appropriate assessment occurs when patients are seen in



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			ophthalmology for other eye conditions? (Akin to having your BP checked at GP's when present for something unrelated).
41	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Statement	RNIB supports this quality statement.
42	The Royal College of General Practitioners	Statement (also p. 2 [list of statements])	<p>The RCGP welcomes the opportunity to comment on this draft standard</p> <p>The phrase "primary care" may be interpreted to mean that GPs should be case finding. In the UK, the majority of cases of chronic open angle glaucoma are detected by community optometrists following a routine sight test. However, there is potential for variability in case finding strategies used. Please change "primary care" to "community optometrists"</p> <p>A survey published in 2011 demonstrated that UK optometrists appear to be well equipped to carry out case finding for chronic open angle glaucoma, although there is a lack of standardisation with respect to equipment used</p> <p><a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1475-1313.2011.00844.x">https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1475-1313.2011.00844.x</a></p>
43	International Glaucoma Association	Rationale	<p>.... They ensure that adults with COAG and related conditions have prompt diagnosis and treatment and people who do not need referral <i>avoid unnecessary anxiety and investigations</i>".</p> <p>Patient feedback included the point "This type of statement really annoys patients. It is clear that what is meant is that it avoids unnecessary cost to the NHS. This is a perfectly valid point" but it was felt the standard should not include "pretend concern for patients" and recommended the statement be changed to ".... They ensure that adults with COAG and related conditions have prompt diagnosis and treatment and people who do not need <i>referral avoid unnecessary further-anxiety and investigations</i>".</p>
44	Optical Confederation	Structure measures a) and b)	Case finding is generally performed in optical practices; if an extended primary care service has been commissioned all practices who are part of this service will have the required equipment, however so do many other practices that are not in an area with a formal scheme. The skills required for case finding are core competencies for optometrists, however many have voluntarily chosen to further demonstrate these skills via an additional postgraduate certification.
45	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Structure measures a) and b)	Do retail optometrists have service agreements that cover providing this information (also applies to 2b)?
46	Royal National Institute of Blind People (RNIB) with	Structure measures a)	Provides little information as a figure alone. Reporting by CCG area would help identify geographical disparities and, by comparing population data, provide indirect measure of equipment and trained staff availability by population.

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	the support of Vision UK	and b)	
47	Royal National Institute of Blind People (RNIB) with the support of Vision UK	New structure measure, c)	Evidence of service level agreements with retail optometrists. Data source: Local data collection, for example, service specifications.
48	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Process measures	Wording of the quality measure lacks clarity – could be interpreted as the proportion of adults who have a case finding test that go on to be referred, measuring referral rate from primary care, rather than measuring the quality of referrals made by primary care.  Amend description wording to: “Proportion of adults referred for further investigation and diagnosis of COAG and related conditions after having case finding tests in primary care”
49	Optical Confederation	Process measure a)	Care needs to be taken to ensure that this measure is not inappropriately used and that both primary and secondary care use the same definitions. As an example, an optical practice may make a referral for OHT, but as the patient does not have COAG it may be erroneously recorded as a false positive referral.
50	Optical Confederation	Process measure b)	Satisfaction can be subjective; there will be a number of patients who meet all of the criteria for referral, but secondary care decide against treating. Some of these patients will be dissatisfied that they were referred and then told that there wasn't anything wrong. This cannot be avoided, but could lead to negative perceptions of optical practices amongst secondary care.
51	International Glaucoma Association	Outcome b)	We feel that a carer survey is not an alternative to a patient survey and suggest the Data source be changed to “Local data collection, for example a patient <i>and</i> carer survey”.
52	International Glaucoma Association	Audience descriptors	Re paragraph ‘Adults with suspected glaucoma and related conditions’  Patient echoed comment 1 (above) and suggested this read “....This means that only people needing further investigations are referred, which may reduce <i>waiting times and cost to the NHS</i> ”.
53	Novartis Pharmaceuticals UK Ltd	Question 1	The recommendation to implement case-finding tests in primary care before referral is a welcome suggestion that aims to improve accurate referrals. This is crucial for glaucoma patients as although the disease is currently incurable, early intervention helps to slow the damage caused to the eye (1). Case-finding tests can also lead to improved access to treatment, which is especially important for glaucoma patients as the disease can lead to blindness in 5 years if untreated, with those with advanced glaucoma at the highest risk of blindness (2).
54	The Industry Vision Group	Question 1	The recommendation to implement case-finding tests in primary care before referral is a welcome suggestion that aims to improve accurate referrals. This is crucial for glaucoma patients as although the disease is currently incurable, early intervention helps to slow the damage caused to the eye (2). Case-finding tests can also lead to improved access to treatment, which is especially important for glaucoma patients as the disease can lead to blindness in 5 years if untreated, with those with advanced glaucoma at the highest risk of blindness (3).  We would also urge this quality statement to include supported access to minimally invasive glaucoma surgery

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			<p>(MIGS) for patients who have not responded to, or have difficulty with, pharmacological treatment. Evidence demonstrates that compliance to eye drops is very poor and 50% patients discontinue taking their medications before 6 months.(4) Evidence suggests that there is significant geographic variation in prescription rates for glaucoma medication across the country, which in part can be explained by changes and variation in practice of eye-care professionals.(5)</p> <p>Despite MIGS being available now for several years as evidence-based treatment for glaucoma, current NICE clinical guidelines (including QS7, which this standard will replace) do not speak to their existence or acknowledge their place in treatment. NICE interventional procedure guidelines have been developed to cover a number of procedures and the publication of this new quality standard is an opportunity to align with those guidelines.</p> <p>As an alternative to earlier forms of more invasive glaucoma surgery, MIGS offer patients both efficacy benefits and a favourable safety profile. MIGS are available as evidence-based treatment for glaucoma, and we encourage NICE to extend their application to patients.</p>
<b>Statement 3</b>			
55	Optical Confederation	[Statement]	No comment
56	Royal National Institute of Blind People (RNIB) with the support of Vision UK	[Statement]	RNIB supports this quality statement.
57	NHS England (Primary Care)	Measure	<p>Cannot fault this (currently referral to assessment 14 days?). This may put more pressure on services and have a knock on effect on other sight loss conditions needing injections though. But this could be seen as an opportunity to combine/co-operate?</p> <p>Monitoring should be straightforward.</p>
58	The Industry Vision Group	Outcome	<p>[...]</p> <p>We suggest that the 'outcome' of interest should be amended to 'reduced loss of vision' to reflect the intended direction of movement.</p>
59	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Outcome a)	The outcome loss of vision (should be defined as loss of 15 letters) and should have gain of vision (gain of 15 letters)
60	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Outcome a)	The outcome loss of vision (should be defined as loss of 15 letters) and should have gain of vision (gain of 15 letters).
61	Novartis Pharmaceuticals	Question 1	We support this quality statement as its application will help to reduce the delays in treatment for patients with late

ID	Stakeholder	Statement number	Comments <sup>4</sup>
	UK Ltd		<p>wet age-related macular degeneration (wet-AMD). Delayed treatment was listed as one of the main causes of permanently reduced vision in a recent surveillance study conducted by the British Ophthalmological Surveillance Unit (BOSU) (3). A study undertaken by the Royal National Institute of Blind People (RNIB) in 2012 also showed that 18 per cent of ophthalmology patients waited for 15 days or longer for diagnosis and treatment.(4) Particularly for wet AMD, the national 18-week referral to treatment (RTT) target is unsuitable for the rapidly developing disease, and NICE’s recommendation for patients to be treated within 14 days should rightly be implemented.(5)</p> <p>We suggest that further information for patients is required in this quality statement. This is in light of a recent High Court decision that allows Clinical Commissioning Groups (CCGs) to encourage the use of an unlicensed medicine for wet-AMD, patients will now have to consider an unlicensed treatment purely on the grounds of cost-saving. It is crucial that patients are appropriately informed of the choices available to them, including accurate information on the licensed medicines available. As such, we suggest that it is stated on page 12 under <i>‘What the quality statement means for different audiences’</i> that the <i>‘agreed protocols’</i> developed by NHS hospital trusts should specify the requirement to obtain and document informed consent when unlicensed medicines are used for treating wet-AMD as recommended in the NICE clinical guideline on Macular degeneration. (6)</p> <p>In a recent statement the RNIB said that “It is vital that patients have the opportunity to have a full discussion with their treating clinician to decide the most appropriate treatment. It is a fundamental principle of the NHS that patients will be involved and consulted on all decisions about their care and treatment (NHSE 2015, GMC2008). This is enshrined in law (The Supreme Court 2015). Patients should be informed of reasons for, and implications of, any changes that are suggested and have the opportunity to discuss these with the treating clinician to make an informed decision. Patients should not feel under pressure to switch or embark on Avastin rather than licensed anti-VEGF drugs because of potential cost savings for the NHS.”</p>
62	The Industry Vision Group	Question 1	<p>We support this quality statement as its application would help to reduce the delays in treatment for patients with late wet age-related macular degeneration (wet-AMD). Delayed treatment was listed as one of the main causes of permanently reduced vision in a recent surveillance study conducted by the British Ophthalmological Surveillance Unit (BOSU).(6) A study undertaken by the Royal National Institute of Blind People (RNIB) in 2012 also showed that 18% of ophthalmology patients waited for 15 days or longer for diagnosis and treatment.(7) Particularly for wet AMD, the national 18-week referral to treatment (RTT) target is unsuitable for the rapidly developing disease, and NICE’s recommendation for patients to be treated within 14 days should rightly be implemented.(8)</p> <p>We suggest that further information for patients is required in this quality statement. This is in light of a recent High Court decision that allows Clinical Commissioning Groups (CCGs) to encourage the use of an unlicensed medicine for wet-AMD, as patients will now have to consider an unlicensed treatment purely on the grounds of cost-saving. It is crucial that patients are appropriately informed of the choices available to them, including accurate information on</p>

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			the licensed medicines available. As such, we suggest that it is stated on page 12 under ' <i>What the quality statement means for different audiences</i> ' that the ' <i>agreed protocols</i> ' developed by NHS hospital trusts should specify the requirement to obtain and document informed consent when unlicensed medicines are used for treating wet-AMD as recommended in the NICE clinical guideline on Macular degeneration.(9)  [...]
63	Macular Society	[Question 2]	This statement is adequate. The lack of systematic audit of wet AMD services will make this standard difficult to measure.
<b>Statement 4</b>			
64	Macular Society	[Statement]	This statement needs to include 'treatment' and a reference to timeliness as in: "Adults with late AMD (wet active) have ongoing monitoring and treatment for both eyes as soon as clinically indicated." As above, the lack of systematic audit, even the lack of electronic patient records in many Trusts, will make this difficult to measure.
65	Roche Products Ltd	Statement	It may be appropriate to define what is considered a clinically appropriate interval for monitoring of both eyes
66	Royal National Institute of Blind People (RNIB) with the support of Vision UK	[Statement]	RNIB supports this quality statement but would like to amend the title to "Monitoring and follow-up treatment of late age-related macular degeneration (wet active). Follow-up treatments for AMD are not addressed elsewhere in the Quality Standard, but there is evidence that a focus on referral to treatment time alone for wet active AMD treatment distorts clinical priorities, and can lead to patients losing sight while waiting for follow-up treatments in order to meet RTT targets.
67	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Statement	Amend to read "Adults with late age-related macular degeneration (AMD) (wet active) have ongoing monitoring and treatment for both eyes.
68	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Rationale	Add before first sentence "Follow-up treatments, within clinically recommended timescales, are essential to ensure that adults with late AMD (wet active) do not suffer avoidable sight loss.
69	NHS England (Primary Care)	Measure	Again agree with aspiration but will need thought on how best to follow up these patients, some adjustment of services to accommodate this and increase capacity may be needed. Again easy to monitor.
70	Optical Confederation	Process measures a) and b)	This monitoring appointment could be delivered in optical practices, helping secondary care to meet targets. It is disappointing that this hasn't been captured in the standards.
71	The Industry Vision Group	Outcome	[...]  We suggest that the 'outcome' of interest should be amended to 'reduced loss of vision' to reflect the intended direction of movement.
72	Royal National Institute of	New outcome	Add the outcome of the 25% delay target for follow up from the national elective care transformation programme.

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	Blind People (RNIB) with the support of Vision UK	measure - b)	
73	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	New outcome measure - b)	Add the outcome of the 25% delay target for follow up from the national elective care transformation programme. <a href="https://future.nhs.uk/connect.ti/ECDC/view?objectId=12183216&amp;exp=e1">https://future.nhs.uk/connect.ti/ECDC/view?objectId=12183216&amp;exp=e1</a> Elective care community of practice. Ophthalmology Failsafe Prioritisation. Access can be granted to relevant NHS applicants by application to <a href="mailto:England.electivecare@nhs.net">England.electivecare@nhs.net</a>
74	Novartis Pharmaceuticals UK Ltd	Question 1	<p>We welcome this quality statement which aims to improve the monitoring and follow-up of wet-AMD patients. The frequency of timely (every four weeks) follow-up for wet-AMD patients cannot be reduced without worsening outcomes.(7)</p> <p>Accurate monitoring of patients with wet-AMD currently requires improvement, as there is a lack of national metrics on eye health. While there are waiting-time targets for newly referred patients, there are no equivalent measures for when patients are seen for follow-up appointments after receiving a diagnosis.(8) Robust monitoring would also improve patient access to timely and appropriate treatment, which is particularly important for wet-AMD which has a fast disease progression.</p> <p>We recommend that attempts should be made to ensure consistency of data capture and that where possible, appropriate measures should be introduced into the National Ophthalmology Database Audit. There have been reports of patients losing vision due to delayed ophthalmology appointments.(9) The most frequent diagnoses were chronic conditions that required regular follow-up, including glaucoma and AMD, and the main cause of delay (in 80% of cases) was a follow-up appointment that occurred beyond the clinically recommended time.(10)</p> <p>We would additionally recommend that this quality statement is expanded to include better data capture of outcomes for patients with wAMD, so that patients and carers can start to assess the quality of their AMD service.</p>
75	The Industry Vision Group	Outcome	<p>The IVG welcomes this quality statement which aims to improve monitoring and follow-up of wet-AMD patients.</p> <p>Accurate monitoring of patients with wet-AMD currently requires improvement, as there is a lack of national metrics on eye health. While there are waiting-time targets for newly referred patients, there are no equivalent measures for when patients are seen for follow-up appointments after receiving a diagnosis.(10) Robust monitoring also improves patient access to timely and appropriate treatment, which is particularly important for wet-AMD which has a fast disease progression.</p> <p>We recommend that attempts should be made to ensure consistency of data capture and that where possible, appropriate measures should be introduced into the National Ophthalmology Database Audit. We also suggest that</p>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			quality statement 4 should reflect the requirement to provide monitoring and treatment at 'clinically appropriate intervals'. There have been reports of patients losing vision due to delayed ophthalmology appointments. The most frequent diagnoses were chronic conditions that required regular follow-up, including glaucoma and AMD(11), and the main cause of delay (in 80% of cases) was a follow-up appointment that occurred beyond the clinically recommended time.(12) [...]
<b>Statement 5</b>			
76	Royal National Institute of Blind People (RNIB) with the support of Vision UK	[Statement]	RNIB supports this quality statement.
77	Royal National Institute of Blind People (RNIB) with the support of Vision UK	[Statement]	Amend the statement to 'Proportion of adults with COAG and related conditions who have reassessment at specific intervals related to their risk of progression as stated by NICE guidance for glaucoma' [...]
78	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Statement	Amend the statement to 'Proportion of adults with COAG and related conditions who have reassessment at specific intervals related to their risk of progression as stated by NICE guidance for glaucoma'.  Similarly amend the numerator to say 'the number in the denominator who have reassessment at specific intervals related to their risk of progression as stated by NG81.
79	International Glaucoma Association	Quality measure a)	Suggest add "... Who have reassessment at specific intervals related to their risk of progression" per NG81
80	NHS England (Primary care)	Quality measure	Following the recommendations already set out and easily monitored. In theory should be straightforward and will have positive impact if done well
81	Optical Confederation	Process measures a) and b)	Again both of these measures could make use of primary care optical practices, reducing pressure on secondary care.
82	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Process measure a)	Amend the statement to 'Proportion of adults with COAG and related conditions who have reassessment at specific intervals related to their risk of progression as stated by NICE guidance for glaucoma'.  Similarly amend the numerator to say 'the number in the denominator who have reassessment at specific intervals related to their risk of progression as stated by NG81.
83	The Royal College of Ophthalmologist, College of Optometrists, Vision	Process measure a)	Amend the statement to 'Proportion of adults with COAG and related conditions who have reassessment at specific intervals related to their risk of progression as stated by NICE guidance for glaucoma'. Similarly amend the numerator to say 'the number in the denominator who have reassessment at specific intervals related to their risk of

ID	Stakeholder	Statement number	Comments <sup>4</sup>
	UK (joint response)		progression as stated by NG81.
84	International Glaucoma Association	Process measure b)	We would welcome inclusion of specific delay targets set out in the ophthalmology Elective Care Transformation Programme.
85	The Industry Vision Group	Outcome	[...]  We suggest that the 'outcome' of interest should be amended to 'reduced loss of vision' to reflect the intended direction of movement.
86	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Outcome a)	Add the outcome of the 25% delay target for follow up from the national elective care transformation programme.
87	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Outcome a)	Add the outcome of the 25% delay target for follow up from the national elective care transformation programme.
88	International Glaucoma Association	Outcome b)	We feel that "... for example a questionnaire." is not robust enough to ensure the scale and depth needed for meaningful patient feedback.
89	Novartis Pharmaceuticals UK Ltd	Question 1	As outlined for quality statement 4, this recommendation also aims to improve the measuring of follow-up appointments. This is important for glaucoma as well as wet-AMD (the focus of quality statement 4) as recent years have seen the worsening of outcomes in glaucoma. As outlined on the Public Health Outcomes Framework, between 2011 and 2014, the number of people with sight loss due to glaucoma declined by -0.2% per 100,000.(11) However, between 2014 and 2017, this small decline has turned into an absolute increase in sight loss among patients with the disease.(12)
90	The Industry Vision Group	Question 1	As outlined for quality statement 4, this recommendation also aims to improve the measuring of follow-up appointments. This is important for glaucoma as well as wet-AMD (the focus of quality statement 4) as recent years have seen the worsening of outcomes in glaucoma. As outlined on the Public Health Outcomes Framework, between 2011 and 2014, the number of people with sight loss due to glaucoma declined by -0.2% per 100,000.(13) However, between 2014 and 2017, this small decline has turned into an absolute increase in sight loss among patients with the disease.(14)  [...].
<b>Statement 6</b>			
91	International Glaucoma Association	Statement	We suggest this should read that patients are 'offered' certification of visual impairment as soon as they are eligible: this would be more accurate and also ensure those declining initially have an opportunity to accept at a later stage. We also suggest that this be extended to all CVI-eligible patients not just those with glaucoma or AMD.
92	Macular Society	[Statement]	This is adequate for wet AMD patients but this statements and the statements as a whole ignore the needs of



ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>people with dry AMD for whom there is no medical treatment available. These are the majority of AMD patients. All AMD patients, but especially dry AMD patients, need emotional and practical support many months, possibly years, before certification is appropriate. This must be addressed in these statements.</p> <p>The level of certification is an imprecise measure as it relies on the efficiency and diligence of disconnected professionals. Many dry AMD patients will be lost in the system as they are not routinely monitored either in primary or secondary care. There is some evidence that rates of CVI completion may depend more on the thoroughness of the local eye clinic staff, e.g. an efficient Eye Clinic Liaison Officer, than it does on the actual number of patients qualifying for a CVI.</p>
93	NHS England (Primary Care)	Statement	It makes sense for anyone to have a CVI for any condition as soon as possible. Does it always have to be a consultant ophthalmologist? It may be easier and quicker if this can be relaxed, plus it may mean they get more of a holistic assessment
94	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Statement	Given that the quality standard is titled 'Serious eye disorders' and to ensure all eligible patients are appropriately offered the opportunity for certification RNIB recommends amending to "Adults with serious eye conditions including late age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are offered certification as soon as eligible."
95	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Statement	<p>Reword the statement to 'Adults with late age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are offered certification as soon as eligible.'</p> <p>Certification is voluntary on the part of the patient and consent is required. Patients may refuse to be certified entirely or may decline in the first instance and change their mind later. [...]</p>
96	Thomas Pocklington Trust	Statement	<p>The wording should be amended to reflect that certification is voluntary. 'Given a CVI' should be replaced with 'offered a CVI' throughout, as follows:</p> <p>Adults with age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are <b>offered</b> a certificate of visual impairment (CVI) as soon as they are eligible.</p>
97	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Structure measure	Reword the structure to 'evidence of local arrangements to ensure that adults with late AMD/COAG are given information about the certificate and those meeting the eligibility criteria are offered a CVI.' In addition, you should add "in a format appropriate to them as detailed in the accessible information standard. It would be ideal to add "in conjunction with support of an ECLO (eye clinic liaison officer)" where possible
98	Thomas Pocklington Trust	Structure measure	<p>The wording should be amended to reflect that certification is voluntary. 'Given a CVI' should be replaced with 'offered a CVI' throughout, as follows:</p> <p>Adults with age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are <b>offered</b> a certificate of visual impairment (CVI) as soon as they are eligible.</p>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
99	Thomas Pocklington Trust	Structure measure	Reword to acknowledge chronic open angle glaucoma (COAG) and the Accessible Information Standard, as follows:  Evidence of local arrangements to ensure that adults with AMD <b>and COAG</b> are given information about the certificate and those meeting the eligibility criteria are offered a certificate of vision impairment. <b>All information provided (including a copy of the CVI) should be provided in the patient's preferred format, in accordance with the Accessible Information Standard.</b>
100	Thomas Pocklington Trust	[Process] measures a) and b)	The wording should be amended to reflect that certification is voluntary. 'Given a CVI' should be replaced with 'offered a CVI' throughout, as follows:  Adults with age-related macular degeneration (AMD) or chronic open angle glaucoma (COAG) are <b>offered</b> a certificate of visual impairment (CVI) as soon as they are eligible.
101	Optical Confederation	Process measures a) and b)	A clear record should be kept of those that are offered CVI registration, but decline. This will help to ensure statistics are accurate.
102	Royal National Institute of Blind People (RNIB) with the support of Vision UK	Process measures a) and b)	The numerator for 6a or 6b doesn't provide a measure that shows that the CVI was given at the right time, just that a CVI was given, and this figure is in relation to those that are eligible. (applies to both the AMF and COAG). This measures a gap but not necessarily the whole gap.
103	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure a)	Reword the process statement to 'Proportion of adults with late AMD that meet the eligibility criteria for a CVI who are offered a CVI.'
104	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure a) – numerator	Reword the numerator to 'the number in the denominator who are offered a CVI.'
105	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure b)	Reword the process statement to 'Proportion of adults with COAG that meet the eligibility criteria for a CVI who are offered a CVI.'
106	The Royal College of Ophthalmologist, College of Optometrists, Vision UK (joint response)	Process measure b) – numerator	Reword the numerator to 'the number in the denominator who are offered a CVI.'
107	The Royal College of	Audience	[...]

ID	Stakeholder	Statement number	Comments <sup>4</sup>
	Ophthalmologist, College of Optometrists, Vision UK (joint response)	descriptors	Certification is voluntary on the part of the patient and consent is required. Patients may refuse to be certified entirely or may decline in the first instance and change their mind later. The text in the standard on page 19 also needs amending to reflect that it is the process of being offered CVI which is most important rather than given to them.
108	Novartis Pharmaceuticals UK Ltd	Question 1	Educating and empowering patients can lead to more effective treatment across the pathway and better adherence to treatment and improved outcomes. A study conducted recently by the RNIB found many participants reported a lack of reassurance and emotional support throughout cataract treatment (13). Post-operatively, patients reported being confused by 'unclear, incomplete and contradictory patient information'. This was partially due to an inconsistency of healthcare professionals seen during consultations. In light of this, NICE should ensure that people with or at risk of developing a serious eye disorder are offered appropriate and accessible patient information at each stage of their patient journey.
109	The Industry Vision Group	Question 1	<p>The IVG supports this quality statement which aims to progress patient access to support regained independence, improved mental health and overall quality of life.</p> <p>Educating and empowering patients can lead to more effective treatment across the pathway and better adherence to treatment and improved outcomes. A study conducted recently by the RNIB found many participants reported a lack of reassurance and emotional support throughout cataract treatment.(15) Post-operatively, patients reported being confused by 'unclear, incomplete and contradictory patient information'. This was partially due to an inconsistency of healthcare professionals seen during consultations. In light of this, NICE should ensure that people with or at risk of developing a serious eye disorder are offered appropriate and accessible patient information at each stage of their patient journey.</p>
110	SeeAbility	[Question 2]	<p>There is no mention of the need for data to be more robust in terms of assessing impact on different groups of the Quality Standard. We know data collection is very poor around equalities and for people with learning disabilities accessing eye care and hospital services so reasonable adjustments can be made  <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12244">https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12244</a></p> <p>But specifically for those with learning disabilities there could now be an opportunity to do this under Quality Standard 6 as the CVI form for certification <b>now has information on any additional needs that the person may have</b>, which includes learning disability or dementia. It would be helpful if the standard could highlight this change to the CVI form.</p>
111	Thomas Pocklington Trust	Question 2	We welcome the inclusion of quality statement 6 within the draft quality standard. The purpose of the CVI is to provide a reliable route for someone with sight loss to access other services, including: social care, benefits and vision rehabilitation. It is also one of the key ways of providing evidence of the prevalence of sight loss and managing the demand for services, both within eye health settings and in wider community and social care services.

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<p>It is the key gateway to registration and all the services and support that flows from that.</p> <p>Numerous people are involved in completing the certification process and each of these professionals (consultant ophthalmologists, registrars, optometrists, medical secretaries, CVI administrators, Eye Clinic Liaison Officers) has the potential to create barriers and delays or to improve outcomes. We are concerned that there is evidence of a 'postcode lottery' in terms of the way eye clinics approach and manage these issues.</p> <p>Some of these factors will impact upon the ability of eye clinics to record and monitor data for the proposed quality measures and these challenges do need to be taken into account. For example, we have heard numerous reports from across the UK of a failure to certify patients at the appropriate time or at all, a failure to complete CVIs and/or a failure of CVIs to be processed efficiently and sent to social services departments.</p> <p>We have heard about barriers such as:</p> <ul style="list-style-type: none"> <li>• The uncertainty of when to certify on the part of the ophthalmologist, particularly for people with long term conditions such as glaucoma or diabetic retinopathy.</li> <li>• External pressures to reduce certification rates, where certification can be seen as a 'failure'.</li> <li>• Clinicians regarding certification as end of process, not a route to services and therefore failing to offer certification when patients are eligible.</li> <li>• Poor awareness of the benefits of being certified and registered, leading to failure to offer certification as clinicians saw no need/little value to patients.</li> <li>• Incorrect assumptions about patients' views and believing patients do not 'need' to be certified.</li> </ul> <p>There is now a substantial body of evidence that patients and health professionals alike have found Eye Clinic Liaison Officers (ECLOs) to be helpful in completing and communicating the CVI process. After the consultant ophthalmologist completes visual acuity information and the primary cause of visual loss, ECLOs can complete the process and explain the implications and benefits to patients. This supports the important role of ECLOs in eye clinics and the need to see them more consistently deployed across the NHS.</p>
<b>Other</b>			
112	Royal National Institute of Blind People (RNIB) with the support of Vision UK	List of statements (p 3)	On page 3, amend Statement 6 to: "Adults with serious eye disorders including AMD or COAG are given a certificate of vision impairment as soon as they are eligible." This is to reflect the suggested change in comment 22 <b>[note: comment 22 is comment 94 in this table]</b> .
113	Royal National Institute of Blind People (RNIB) with the support of Vision UK	List of statements from quality standard 7 on	Page 4 - this is the first time that acronyms "IOP", "OHT" and "MMC" are used, and should be explained here.

ID	Stakeholder	Statement number	Comments <sup>4</sup>
		glaucoma (p. 4)	
<b>References – Novartis</b>			
<p>1) King, A et.al (2013). Glaucoma – clinical review British Medical Journal 346:1 pp.29-33. Page 29. Available online: <a href="http://www.bmj.com/bmj/section-pdf/187924?path=/bmj/346/7912/Clinical_Review.full.pdf">http://www.bmj.com/bmj/section-pdf/187924?path=/bmj/346/7912/Clinical_Review.full.pdf</a></p> <p>2) Ibid</p> <p>3) Foot B, MacEwen C (2017). Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Eye (Lond); 31(5):771-775. Available at: <a href="https://www.ncbi.nlm.nih.gov/pubmed/28128796">https://www.ncbi.nlm.nih.gov/pubmed/28128796</a></p> <p>4) The Royal College of Ophthalmologists (2013). Age-Related Macular Degeneration: Guidelines for Management. September. Available from: <a href="https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-318-RCOphth-AMD-Guidelines-Sept-2013-FINAL-2.pdf">https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-318-RCOphth-AMD-Guidelines-Sept-2013-FINAL-2.pdf</a></p> <p>5) NICE (2018). Age-related macular degeneration recommendations. Page 7. Available online, accessible here: <a href="https://www.nice.org.uk/guidance/ng82/chapter/Recommendations#diagnosis-and-referral">https://www.nice.org.uk/guidance/ng82/chapter/Recommendations#diagnosis-and-referral</a></p> <p>6) Ibid.</p> <p>7) Amoaku, W et.al (2012). Action on AMD Optimising patient management: act now to ensure current and continual delivery of best possible patient care. Macmillan Publishers Limited. Available at: <a href="https://www.nature.com/articles/eye2011343#aff2">https://www.nature.com/articles/eye2011343#aff2</a></p> <p>8) All Party Parliamentary Group on Eye Health and Visual Impairment (2018). See the light: Improving capacity in NHS eye care in England Page seven. Available online, accessible here: <a href="https://www.rnib.org.uk/sites/default/files/See%20the%20light_Improving%20NHS%20eye%20care%20capacity%20in%20England_0.pdf">https://www.rnib.org.uk/sites/default/files/See%20the%20light_Improving%20NHS%20eye%20care%20capacity%20in%20England_0.pdf</a></p> <p>9) Foot B, MacEwen C (2017). Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Op cit.</p>			

ID	Stakeholder	Statement number	Comments <sup>4</sup>
10)	Ibid		
11)	IVG (2018).	Evidence Audit: Regional ophthalmology outcomes.	
12)	IVG (2018).	Evidence Audit: Regional ophthalmology outcomes.	
13)	Royal National Institute of Blind People (2017).	Pre- and post-operative cataract services – ensuring patient centred care	<i>Royal National Institute of Blind People</i>
	Available at:		
			<a href="https://www.google.co.uk/url?sa=t&amp;rct=j&amp;q=&amp;esrc=s&amp;source=web&amp;cd=1&amp;cad=rja&amp;uact=8&amp;ved=0ahUKEwi7tbTItDYaWI4KQKHR4qBGYQFggpMAA&amp;url=https%3A%2F%2Fwww.mib.org.uk%2Fsites%2Fdefault%2Ffiles%2FCataract%2520policy%2520roundtable%2520evidence%2520briefing.docx&amp;usg=AOvVaw0v91MQkEN5a_qOG-5avR8U">https://www.google.co.uk/url?sa=t&amp;rct=j&amp;q=&amp;esrc=s&amp;source=web&amp;cd=1&amp;cad=rja&amp;uact=8&amp;ved=0ahUKEwi7tbTItDYaWI4KQKHR4qBGYQFggpMAA&amp;url=https%3A%2F%2Fwww.mib.org.uk%2Fsites%2Fdefault%2Ffiles%2FCataract%2520policy%2520roundtable%2520evidence%2520briefing.docx&amp;usg=AOvVaw0v91MQkEN5a_qOG-5avR8U</a>
14)	Public Health England (2014)	Diabetes no longer leading cause of blindness thanks to screening.	Available at: <a href="https://www.gov.uk/government/news/diabetes-no-longer-leading-cause-of-blindness-thanks-to-screening">https://www.gov.uk/government/news/diabetes-no-longer-leading-cause-of-blindness-thanks-to-screening</a>
15)	Scanlon PH (2008)	The English National Screening Programme for Sight-Threatening Diabetic Retinopathy,	Journal of Medical Screening 15:1 pp.1-4
16)	All Party Parliamentary Group on Eye Health and Visual Impairment (2018).	See the light: Improving capacity in NHS eye care in England.	Op cit.
17)	Ibid.		
18)	IVG (2018).	Evidence Audit: Regional ophthalmology outcomes.	
19)	bid		
20)	The Royal College of Ophthalmologists (RCO).	(2017). Workforce Census 2016: A picture of the size and shape of the UK ophthalmic medical workforce.	Available

ID	Stakeholder	Statement number	Comments <sup>4</sup>
			online, accessible here: <a href="https://www.rcophth.ac.uk/2017/03/workforce-census-2016-a-picture-of-the-size-and-shape-of-the-uk-ophthalmic-medical-workforce/">https://www.rcophth.ac.uk/2017/03/workforce-census-2016-a-picture-of-the-size-and-shape-of-the-uk-ophthalmic-medical-workforce/</a>
		21)	Ibid. Page one and two.
		22)	The Royal College of Ophthalmologists (RCO). (2018). National Tariff Consultation June 2018, RCOphth, RNIB, IGA and Macular Society collaborate on response. Page 3. Available online, accessible here: <a href="https://www.rcophth.ac.uk/2018/06/national-tariff-consultation-june-2018-rcophth-rnib-iga-and-macular-society-collaborate-on-responses/">https://www.rcophth.ac.uk/2018/06/national-tariff-consultation-june-2018-rcophth-rnib-iga-and-macular-society-collaborate-on-responses/</a>
		23)	Boyce, T. et al (2013). Projecting number of falls related to visual impairment. <i>British Journal of Healthcare Management</i> . Vol 19 226-229.
<b>References – The Industry Vision Group</b>			
		(1)	The Royal College of Ophthalmologists (2017). 66% of Clinical Leads surveyed by the RCOphth confirm cataract rationing is restricting access to surgery. Available at: <a href="https://www.rcophth.ac.uk/2017/11/cataract-rationing-survey-reveals-66-of-responding-eye-units-have-some-restrictions-to-access-surgery/">https://www.rcophth.ac.uk/2017/11/cataract-rationing-survey-reveals-66-of-responding-eye-units-have-some-restrictions-to-access-surgery/</a>
		(2)	King, A et.al (2013). Glaucoma – clinical review <i>British Medical Journal</i> 346:1 pp.29-33. Page 29. Available at: <a href="http://www.bmj.com/bmj/section-pdf/187924?path=/bmj/346/7912/Clinical_Review.full.pdf">http://www.bmj.com/bmj/section-pdf/187924?path=/bmj/346/7912/Clinical_Review.full.pdf</a>
		(3)	Ibid.
		(4)	Nordstrom BL, Friedman DS, Mozaffari E, Quigley HA, Walker AM (2005). Persistence and adherence with topical glaucoma therapy. <i>Am J Ophthalmol</i> . 140(4):598-606.
		(5)	Heng, JS et.al (2016). Geographical variation in glaucoma prescribing trends in England 2008-2012: an observational ecological study <i>British Medical Journal</i> Available at: <a href="https://www.researchgate.net/publication/303322373_Geographical_variation_in_glaucoma_prescribing_trends_in_England_2008-">https://www.researchgate.net/publication/303322373_Geographical_variation_in_glaucoma_prescribing_trends_in_England_2008-</a>

ID	Stakeholder	Statement number	Comments <sup>4</sup>
<a href="#">2012 An observational ecological study</a>			
(6) Foot B, MacEwen C (2017). Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. <i>Eye (Lond)</i> ; 31(5):771-775. Available at: <a href="https://www.ncbi.nlm.nih.gov/pubmed/28128796">https://www.ncbi.nlm.nih.gov/pubmed/28128796</a>			
(7) The Royal College of Ophthalmologists (2013). Age-Related Macular Degeneration: Guidelines for Management. September. Available at: <a href="https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-318-RCOphth-AMD-Guidelines-Sept-2013-FINAL-2.pdf">https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-318-RCOphth-AMD-Guidelines-Sept-2013-FINAL-2.pdf</a>			
(8) NICE (2018). Age-related macular degeneration recommendations. Page seven. Available at: <a href="https://www.nice.org.uk/guidance/ng82/chapter/Recommendations#diagnosis-and-referral">https://www.nice.org.uk/guidance/ng82/chapter/Recommendations#diagnosis-and-referral</a>			
(9) Ibid.			
(10) All Party Parliamentary Group on Eye Health and Visual Impairment (2018). See the light: Improving capacity in NHS eye care in England. Page seven. Available at: <a href="https://www.rnib.org.uk/sites/default/files/See%20the%20light_Improving%20NHS%20eye%20care%20capacity%20in%20England_0.pdf">https://www.rnib.org.uk/sites/default/files/See%20the%20light_Improving%20NHS%20eye%20care%20capacity%20in%20England_0.pdf</a>			
(11)Foot B, MacEwen C (2017). Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Op cit.			
(12) Ibid.			
(13) IVG (2018). Evidence Audit: Regional ophthalmology outcomes.			
(14)IVG (2018). Evidence Audit: Regional ophthalmology outcomes.			
(15) Royal National Institute of Blind People (2017). Pre- and post-operative cataract services – ensuring patient centred care; <i>Royal National Institute of Blind People</i> Available at:			



ID	Stakeholder	Statement number	Comments <sup>4</sup>
			<a href="https://www.google.co.uk/url?sa=t&amp;rct=j&amp;q=&amp;esrc=s&amp;source=web&amp;cd=1&amp;cad=rja&amp;uact=8&amp;ved=0ahUKEwi7tbTltdDYAhWI4KQKHR4qBGYQFggpMAA&amp;url=https%3A%2F%2Fwww.nib.org.uk%2Fsites%2Fdefault%2Ffiles%2FCataract%2520policy%2520roundtable%2520evidence%2520briefing.docx&amp;usg=AOvVaw0v91MQkEN5a_qOG-5avR8U">https://www.google.co.uk/url?sa=t&amp;rct=j&amp;q=&amp;esrc=s&amp;source=web&amp;cd=1&amp;cad=rja&amp;uact=8&amp;ved=0ahUKEwi7tbTltdDYAhWI4KQKHR4qBGYQFggpMAA&amp;url=https%3A%2F%2Fwww.nib.org.uk%2Fsites%2Fdefault%2Ffiles%2FCataract%2520policy%2520roundtable%2520evidence%2520briefing.docx&amp;usg=AOvVaw0v91MQkEN5a_qOG-5avR8U</a>
		(16)	Public Health England (2014). Diabetes no longer leading cause of blindness thanks to screening. Available at: <a href="https://www.gov.uk/government/news/diabetes-no-longer-leading-cause-of-blindness-thanks-to-screening">https://www.gov.uk/government/news/diabetes-no-longer-leading-cause-of-blindness-thanks-to-screening</a>
		(17)	Scanlon PH (2008). The English National Screening Programme for Sight-Threatening Diabetic Retinopathy, Journal of Medical Screening 15:1 pp.1-4
		(18)	All Party Parliamentary Group on Eye Health and Visual Impairment (2018). See the light: Improving capacity in NHS eye care in England. Op cit.
		(19)	Ibid.
		(20)	IVG (2018). Evidence Audit: Regional ophthalmology outcomes.
		(21)	Ibid.
		(22)	The Royal College of Ophthalmologists (RCO). (2017). Workforce Census 2016: A picture of the size and shape of the UK ophthalmic medical workforce. Available at: <a href="https://www.rcophth.ac.uk/2017/03/workforce-census-2016-a-picture-of-the-size-and-shape-of-the-uk-ophthalmic-medical-workforce/">https://www.rcophth.ac.uk/2017/03/workforce-census-2016-a-picture-of-the-size-and-shape-of-the-uk-ophthalmic-medical-workforce/</a>
		(23)	Ibid. Page one and two.
		(24)	The Royal College of Ophthalmologists (RCO). (2018). National Tariff Consultation June 2018, RCOphth, RNIB, IGA and Macular Society collaborate on response. Page 3. Available at: <a href="https://www.rcophth.ac.uk/2018/06/national-tariff-consultation-june-2018-rcophth-rnib-iga-and-macular-society-collaborate-on-responses/">https://www.rcophth.ac.uk/2018/06/national-tariff-consultation-june-2018-rcophth-rnib-iga-and-macular-society-collaborate-on-responses/</a>
		(25)	Boyce, T. et al (2013). Projecting number of falls related to visual impairment. British Journal of Healthcare Management. Vol 19 226-229.

### ***Registered stakeholders who submitted comments at consultation***

- Alcon Eye Care UK Ltd (A Novartis division)
- Alliance Pharma PLC
- Bayer PLC
- International Glaucoma Association
- Macular Society
- Newmedica
- NHS England (Primary Care)
- Novartis Pharmaceuticals UK Ltd
- Optical Confederation
- Roche Products Ltd
- Royal College of Nursing
- Royal National Institute of Blind People (RNIB)
- SeeAbility
- The College of Optometrists
- The Industry Vision Group - Allergan (Chair), Bayer PLC, Glaukos, Novartis, Santen and Shire)
- The Royal College of General Practitioners
- The Royal College of Ophthalmologists
- Thomas Pocklington Trust

- University Hospitals Bristol NHS Foundation Trust
- Vision UK

**Note:**

- Royal National Institute of Blind People (RNIB) submitted a response with the support of Vision UK.
- The College of Optometrists, The Royal College of Ophthalmologists and Vision UK submitted a joint response.

## Appendix 2: Quality standard consultation comments table – respondents with links to the tobacco industry

ID	Stakeholder	Statement number	Comments <sup>5</sup>
<b>Statement 3</b>			
01	Bayer PLC	General	<p>We support the inclusion of quality statement 3. ‘Delayed treatment’ was listed as one of the main causes of delay in a recent surveillance study through the British Ophthalmological Surveillance Unit (BOSU) published by Foot et al.2017<sup>1</sup> which showed that “patients are suffering preventable harm due to health service initiated delay leading to permanently reduced vision.” A study undertaken by the RNIB in 2012 also showed that 18 per cent or people waited for 15 days or longer for diagnosis and treatment.<sup>2</sup></p> <p>Therefore we agree that timely treatment is a key area for quality improvement.</p> <p>(1) Foot B, MacEwen C. Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Eye (Lond) 2017; 31(5):771-775.</p> <p>(2) Royal National Institute of Blind People (BNIB). Don't lose sight! Don't delay! Perspectives on the wet age-related macular degeneration (wet AMD) patient journey. RNIB Website. 2013 Available from: <a href="https://www.rnib.org.uk/sites/default/files/Don%27t%20lose%20sight%20don%27t%20delay%20Campaign%20report.pdf">https://www.rnib.org.uk/sites/default/files/Don%27t%20lose%20sight%20don%27t%20delay%20Campaign%20report.pdf</a></p>
02	Bayer PLC	Outcome	For quality statements 3 and 4 we suggest that the ‘outcome’ of interest should be amended to ‘ <i>reduced</i> loss of vision’ to reflect the intended direction of movement.
03	Bayer PLC	Audience descriptors	For quality statement 3 we suggest that it is stated on page 12 under ‘ <i>What the quality statement means for different audiences</i> ’ that the ‘ <i>agreed protocols</i> ’ developed by NHS hospital trusts should specify the requirement to obtain and document informed consent when unlicensed medicines are used for treating late AMD (wet active) as recommended in the NICE clinical guideline on Macular degeneration (NG82).
<b>Statement 4</b>			
04	Bayer PLC	Statement	We suggest that quality statement 4 should reflect the requirement to provide monitoring at ‘clinically appropriate intervals’ as discussed in the supporting information. We are concerned that the current proposal would allow for the measure to be met simply by having a monitoring appointment scheduled irrespective of the interval.

<sup>5</sup>PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments <sup>5</sup>
			<p>We also suggest the statement be broadened to specify that treatment should also be delivered at clinically appropriate intervals.</p> <p>There have been reports of patients losing vision due to delayed ophthalmology appointments based upon evidence available from the National Reporting and Learning System (NRLS),<sup>1</sup> and also from a more recent surveillance study through the British Ophthalmological Surveillance Unit (BOSU) published by Foot et al.2017,<sup>2</sup> which showed that “patients are suffering preventable harm due to health service initiated delay leading to permanently reduced vision.” In this study the most frequent diagnoses of those who lost vision due to delays in care were chronic conditions that required regular follow-up, including glaucoma and AMD, and the main cause of delay (in 80% of cases) was a follow-up appointment that occurred beyond the clinically recommended time.</p> <p>There is also evidence, from UK real-world studies, of variation in intravitreal anti-VEGF injection frequency and visual acuity outcomes between sites attempting to provide the same therapeutic regime.<sup>3;4</sup></p> <p>The publication by Foot et al. 2017<sup>2</sup> discusses that “<i>at present, in contrast to appointments and treatment following initial (or new) referrals, there are no targets or penalties imposed for hospitals that delay or re-book follow-up appointments to beyond the time interval recommended by the clinician,</i>” and that “<i>this is despite review patients being significantly more likely to have confirmed pathology that may lead to vision loss and as demonstrated, delays for follow-up patients are resulting in this kind of harm.</i>”</p> <p><b>Proposed amendment:</b> Adults with late age-related macular degeneration (AMD) (wet active) have ongoing monitoring for both eyes and treatment at clinically appropriate intervals.</p> <p>(1) The Royal College of Ophthalmologists. News: BOSU report shows patients coming to harm due to delays in treatment and follow-up appointments. The Royal College of Ophthalmologists website. 2017. Available from: <a href="https://www.rcophth.ac.uk/2017/02/bosu-report-shows-patients-coming-to-harm-due-to-delays-in-treatment-and-follow-up-appointments/">https://www.rcophth.ac.uk/2017/02/bosu-report-shows-patients-coming-to-harm-due-to-delays-in-treatment-and-follow-up-appointments/</a></p> <p>(2) Foot B, MacEwen C. Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Eye (Lond) 2017; 31(5):771-775.</p> <p>(3) Talks JS, James P, Sivaprasad S, Johnston RL, McKibbin M. Appropriateness of quality standards for meaningful intercentre comparisons of aflibercept service provision for neovascular age-related macular degeneration. Eye (Lond) 2017; 31(11):1613-1620.</p> <p>(4) Liew G, Lee AY, Zarranz-Ventura J, Stratton I, Bunce C, Chakravarthy U et al. The UK Neovascular AMD Database Report 3: inter-centre variation in visual acuity outcomes and establishing real-world measures of care.</p>

ID	Stakeholder	Statement number	Comments <sup>5</sup>
			Eye (Lond) 2016; 30(11):1462-1468.
05	Bayer PLC	Outcome	For quality statements 3 and 4 we suggest that the 'outcome' of interest should be amended to 'reduced loss of vision' to reflect the intended direction of movement.
06	Bayer PLC	Data source	For quality statement 4, the recommendations for 'data sources' predominantly appear to be 'local data collection'. We suggest that attempts should be made to ensure consistency of data capture and that where possible, appropriate measures should be introduced into the National Ophthalmology Database Audit.