NICE Guideline: Diabetic retinopathy, scoping workshop notes

Workshop date 17 December 2021

Draft Scope: overall impression • Does the scope make sense? • Overall, do we have the right focus?	Overall stakeholders welcomed that NICE was developing the Diabetic retinopathy guideline. They agreed that the draft scope covers the main areas of the diabetic retinopathy management and monitoring pathway. Stakeholders discussed the issues that may occur with some of the overlaps between screening and hospital eye services. They noted the progressive nature of retinopathy, that it is important that those with retinopathy needing treatment is not seen as a failure, and that there can be some stigma around getting treatment. Stakeholders discussed the inclusion of paediatric patients and agreed that they should be included. Stakeholders agreed that the group that is included in the national eye screening programme may be considered those with background retinopathy and that this guideline is more for people already referred on from the screening programme. Stakeholders discussed the risk

	of retinopathy with the possible rapid reduction in HbA1c with pregnancy (and other groups such as people going on closed glucose loops and artificial pancreas technology) and whether these groups are included in the guideline. Stakeholders discussed the importance of the wellbeing, mental health and emotional needs at various relevant points in the pathway.
Section 2: Who the guideline is for This guideline is for: • Healthcare professionals in secondary care. • Practitioners in ophthalmic and optometric services • People using these services, their families, and carers. It may also be relevant for: • Healthcare professionals in primary care (such as general practitioners) • Commissioners and providers of ophthalmic and optometric services. • NHS Diabetic Eye Screening Programme Is there anyone else this guideline should be for?	The stakeholders were happy with the groups listed here. Some stakeholders felt that diabetologists, rehabilitation services, clinicians' liaisons and local authority sensory assessors should be considered on this list. Stakeholders noted the importance of the communication between the clinicians who are managing diabetes and ophthalmic services. Stakeholders noted that there are ongoing changes to commissioning models that may impact on the set up of future services.

Section 3.1 Who is the focus? Groups that will be covered People diagnosed with diabetic retinopathy Are the inclusions from the draft scope correct? Specific consideration will be given to the groups identified in the equality impact assessment form Are there any groups we should give specific consideration to? The EIA proposes that we give specific considerations to - Ethnic groups – Black and Asian ethnic minority groups – there is evidence that in the UK prevalence of diabetic retinopathy is higher in these groups – maybe linked to thinner retinas - Pregnant women who have a diagnosis of type 1 and type 2 diabetes – progression for diabetic retinopathy is increased during pregnancy.	The stakeholders were happy with the main group that will be covered in the guideline. For special considerations they agreed with including pregnant women and the identified ethnic groups. The stakeholders identified white British males from deprived areas as a group that consistently have some of the poorest outcomes with diabetic retinopathy. This was a finding from a recent National diabetes audit report. Stakeholders discussed that this could be considered in the equality impact assessment and as a possible subgroup where data is available. Some stakeholders also said it was important to include people who had kidney or kidney-pancreas transplant, even for those who no longer require insulin their diabetic retinopathy may still progress, but patients may not realise the need to continue to get this monitored. In addition, stakeholders provided the following suggestions for populations needing consideration in any further sub-group analyses: people with developmental delays, people

	having dialysis, people with certain comorbidities, people taking drugs that may increase macular oedema.
Section 3.2 Settings **Settings that will be covered** All settings in which NHS-funded care is received. Are there any other settings that should be included? Within the NHS-funded care, are there any settings that should be excluded?	Stakeholders thought the following settings should be covered • Local authorities
Section 3.3 Activities, services or aspects of care and Section 3.5 Key issues and questions **We are proposing this guideline will cover 2 areas:** • Management • Monitoring	The stakeholders did not have any additions to the currently proposed areas for this guideline. Stakeholders discussed the lack of evidence for any long-term effects and impacts in many of the trials. They noted that some of those treated for retinopathy are quite young and knowing long-term effects of treatments are important.

We have drafted the following questions to consider management of retinopathy. 1.1. What clinical features predict progression of non-proliferative diabetic retinopathy (NPDR) to vision threatening diabetic retinopathy including a) proliferative diabetic retinopathy b) diabetic macular oedema c) diabetic macular ischaemia?	Stakeholders agreed with this question. They discussed some of the clinical features that may be identified in the evidence. There were some concerns that this question may overlap with the NHS Diabetic Eye Screening programme. Stakeholders explained that the R2 diabetic retinopathy threshold covers a wide range of patients, this question will help consider the features that may predict progression following identification of retinopathy. They also noted that there are patients who are referred from other areas as well as the screening service. In addition, stakeholders explained that the specificity of the referral tests can be quite low, resulting in a high percentage of those who are referred from screening to hospital that may not actually need hospital follow-up. They mentioned technologies such as the optometric coherence tomography's specificity is much better and can better identify those who need immediate treatment. However, they advised that this is not in use in most NHS diabetic eye screening programmes and some hospital

	eye services; therefore it will be good to include a question that can provide some insight on more specific thresholds.
1.2 What is the threshold/criteria to initiate treatment of diabetic retinopathy and diabetic maculopathy?	The stakeholders agreed that this area should be included. They thought that it complemented question 1.1.
1.3 What strategies are effective in preventing and/or reducing the risk of progression of non-proliferative diabetic retinopathy (NPDR) to vision threatening diabetic retinopathy, including to proliferative diabetic retinopathy, diabetic macular oedema and macular ischaemia, including o reducing levels of glycaemia o lipid lowering agents (such as fibrates and statins), o light therapies (including light emitting sleep mask) o anti-vascular endothelial growth factor (anti-VEGF) agents (such as aflibercept, ranibizumab), o intravitreal steroids	Stakeholders acknowledged the value of including this question. They discussed that reducing glycaemia levels is part of managing diabetes, and targets for diabetes are the same as those for diabetic retinopathy. However, they noted that there is some concern relating to retinopathy progression with rapid reduction of HbA1c and this should be part of this review. They also thought that there could be consideration of any impact of blood pressure lowering on prevention or progression of retinopathy, as part of this question.

1.4 What is the effectiveness and cost effectiveness of different management strategies in the treatment of proliferative diabetic retinopathy, including (alone or in combination) ○ laser photocoagulation panretinal photocoagulation, targeted retinal photocoagulation) ○ anti-vascular endothelial growth factor agents (such as aflibercept, ranibizumab) ○ vitrectomy (surgery)	Overall, the stakeholders agreed with the inclusion of this question. They emphasised the importance of factoring long term benefits, however they acknowledged that it may be difficult to find studies on this.
1.5 What is the effectiveness and cost effectiveness of different management strategies in the treatment of diabetic macular oedema, including (alone or in combination) ○ intravitreal steroids (such as fluocinolone acetonide, dexamethasone) ○ laser photocoagulation (micro-pulse subthreshold macular laser, standard threshold macular laser) ○ anti-vascular endothelial growth factor agents (such as aflibercept, ranibizumab) ○ vitrectomy (surgery)	The stakeholders agreed with the inclusion of this question. There were concerns regarding making sure that the guideline remains valid, stakeholders noted that there are new oral therapies currently in clinical trials that may impact this area in the future.

1.6 What are the clinical features or factors that suggest treatment should be chosen, switched, or stopped for people diagnosed with a) proliferative diabetic retinopathy b) diabetic macular oedema?	The stakeholders agreed with the inclusion of this question, they thought that this is an important question for patients. Again, the possible lack of evidence for longer term outcomes was discussed. They also discussed if the question could also look at wider psycho-social factors that might impact on treatment choice, for example treatments that involve fewer injections for people who have fear of injections or the frequency of treatments, as these may well influence the decisions around the choice of treatments used. They also discussed the need for consideration of patient preferences and shared decision making.
1.7 What is the most effective treatment strategy for managing diabetic retinopathy with cataract surgery?	The stakeholders agreed with the inclusion of this question. They said it was important because many patients are currently discharged to community ophthalmologists, but it may be more appropriate for some to be followed up in the hospital eye service. They thought that this question should consider pre-op and post-op treatment strategies. Stakeholders also added that there are other comorbidities that could be included in the subgroups considered in

	the review questions, for example sickle cell disease and rheumatoid arthritis.
Monitoring diabetic retinopathy 2.1 How often should people with diabetic retinopathy, and have been referred to the hospital eye services, but are not receiving treatment be reviewed?	Stakeholders welcomed this question. They explained the complexities around the patient journey between the hospital eye services and the screening programme. They explained that in some cases patients are referred to the hospital eye services and discharged back to the screening programme and get referred back to the hospital eye services at the next screening. Others are referred to the digital surveillance programme where they are monitored until a time when they are referred to the hospital eye services. Stakeholders thought that this question will help address these complexities. Stakeholders also discussed that the patient journey varies considerably across screening programmes and hospital services. Stakeholders also mentioned that there is a loss of patients with referral from hospitals back to screening services putting patients at risk of going without surveillance. They were concerned that patients may be given limited information and it is important that they understand where they are on the

2.2 How often should people with complications of diabetic retinopathy who are receiving treatment or have received treatment be reviewed?	pathway. Some stakeholders wondered if the question should also address best way to monitor these patients, for example virtual versus face to face. The stakeholders welcomed this question and they mentioned that surveillance in hospital eye services varies across country.
Additional comments	The stakeholders discussed if a question should be included about additional needs for people diagnosed with/going through treatment for diabetic retinopathy. Information needs to be provided because of the emotional/mental health needs that come with this diagnosis and the risk of progression and sight loss. Stakeholder thought it was very important to consider this – people need to be able to access information /support at every stage of the pathway. They discussed the role of the eye clinic liaison officers and the importance of this role for people with retinopathy, at any

	stage of the pathway, but also noted that these officers are not available in all hospital eye services.
We are proposing that the guideline will not cover these areas: 1 Areas that are covered by the NHS Diabetic Eye Screening Programme and these are: o Routine annual screening. o Screening in surveillance clinic. o Detection and identification of referrable diabetic retinopathy. 2 Prevention of diabetic retinopathy - this is included in the following NICE guidelines as a long-term vascular complication: - Diabetes (type 1 and type 2) in children and young people: diagnosis and management - Type 1 diabetes in adults: diagnosis and management	The stakeholders agreed with these areas not being covered in the guideline.

Section 3.6 Main outcomes The draft scope has listed the following outcomes. These are broad to allow the committee to consider which outcomes they would like to look at for each question. • Best-corrected visual acuity (BCVA) and macular thickness changes • Central and peripheral vision loss • Progression of diabetic retinopathy, progression to diabetic macular oedema or proliferative diabetic retinopathy • Regression of diabetic retinopathy • Treatment related pain • Quality of life • Acceptability of treatment to patients **Any comments?**	The stakeholders agreed with the list of outcomes and no specific additions were made.

Committee constituency 2* Consultant ophthalmologists 1* Paediatric ophthalmologist 1* Ophthalmic surgeon 1* Specialist Ophthalmology Nurse 2* lay members 1* Optometrist 1* GP	Stakeholders suggested the following roles should be considered for committee recruitment: commissioners, adult and paediatric diabetes consultants (possibly as co-opted members), diabetes nurse specialist (possibly co-opted member) and eye clinic liaison officers.