

*The* ROYAL COLLEGE *of*  
OPHTHALMOLOGISTS

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## The Way Forward

Options to help meet demand  
for the current and future care of  
patients with eye disease

Age-Related Macular Degeneration  
and Diabetic Retinopathy

# The Way Forward

## Age-related Macular Degeneration and Diabetic Retinopathy

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The Royal College of Ophthalmologists commissioned this project in response to an increasing awareness that **the number of patients with Diabetic Retinopathy and Age-related Macular Degeneration is growing across the UK without a commensurate growth in the number of ophthalmologists and other resources available to treat those patients.**

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***New ways of working are not the solution, but do form part of it***

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In order to help Royal College members who are already facing the challenges that our growing elderly and diabetic population presents to the services they lead, this project aims to capture some of the innovations and service redesigns from different units around the UK. These options are presented in this report in order to inform consultant colleagues who are wishing to improve efficiency and create services that are sustainable in the face of the growing disparity between demand and resource. **These new ways of working are not the solution, but do form part of it. More ophthalmologists, more eye healthcare professionals (HCPs), more space, more resource as well as more efficient ways of working are urgently needed.**



Peer reviewed and grey literature was searched, and **telephone interviews conducted with more than 200 consultants leading their services across the sub-specialities in the UK**, looking for

opportunities for shared learning. It is clear that one size will not fit all; however, it is equally clear, that every eye department is going to be challenged by the increase in demand and may have to progress to new models of working in the rapidly changing world of Medical Retina service delivery.

**The Way Forward project aims to equip ophthalmologists with tools to estimate and evaluate the size of the growth in demand that can be expected over the next 20 years, and most importantly, to offer some practical options for dealing with that growth gleaned from what our colleagues in other departments around the country are already doing.** The project also aims to provide a substrate and mechanisms for practical peer support and networks where possible. In addition the advice in the documents aims to be in line with the RCOphth sustainability objectives (appendix D).

**Members can email: [wayforward@rcophth.ac.uk](mailto:wayforward@rcophth.ac.uk) for more information.**

# UK 2016–2035: More people, more older people, more need for eye care

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The demographic changes in the earth's population are well known; there are more people, and those people are living longer. The recent development of new but recurrent long-term treatments for some retinal diseases adds further demand to the previous standard of care. The effect of these changes on ophthalmic services is clear, with The Royal College of Ophthalmologists (RCOphth) President, Prof Carrie MacEwen, describing the situation as:

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***“a perfect storm of increased demand, caused by more eye disease in an ageing population requiring long term care”<sup>1</sup>***

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The commissioning of The Way Forward project, the methodology for which is presented in appendix A, was driven by awareness of the growth in the elderly population alongside the absence of commensurate growth in either financial or human resources to deal with the increasing burden of ophthalmic disease. Appeals by the RCOphth to have the number of UK ophthalmic training posts increased have been declined to date, and the previous practice of importing ophthalmologists from around the world may be less easy as a global shortage of ophthalmologists is reported,<sup>2</sup> and there is recognition of the existence of ethical issues around attracting staff from the national health systems of countries with greater ophthalmic human resource problems than the UK<sup>3-6</sup>.

There is the acute necessity therefore to plan for a future in which the volume of eye care service delivered per ophthalmologist can be increased. Efficient Medical Retina services are an essential part of that future landscape. As options for dealing with the demands put on services are discussed, consideration must be given to the issue of long term sustainability. We have a duty of care to take into account the social impact on the people involved in the services, the economic sustainability as well as the environmental impact; this is the so-called Triple Bottom Line that must be met as we pay due regard to the people, the profitability and the planet.

In order to facilitate service capacity and workforce planning for Medical Retina services, it is necessary to attempt to quantify the expected growth in demand due to Age-related Macular Degeneration (AMD) and Diabetic Retinopathy (DR). Slightly different approaches to the quantification are required as the risk factors, and age of onset for the two chronic retinal diseases are different. For AMD, with the major risk factor being age, we need to understand the expected future demographic changes and apply prevalence data from existing population based surveys to those. For diabetes, although age is a risk factor, obesity, genetics and other lifestyle factors are also at play whose future influence is harder to model.

## AMD Projections for the UK 2015–2035

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In order to quantify the expected growth in AMD case numbers, projections of age stratified population growth, as produced by the Office for National Statistics (ONS) were taken and prevalence estimates from population based surveys applied to these projections.



**8.9m by 2035**

The growth in the elderly population is exemplified in the fact that in 2010 there were estimated to be 4.9 million UK residents over 75 years of age (1.4 million >85 years). By 2035 the population over 75 years is expected to be more than 80% larger at 8.9 million, and the population over 85 years of age will be 2.5 times larger at 3.5 million. The ratio, therefore, of those of working age compared to those of retirement age will drop from 3.16 in 2010 to 2.87 by mid-2035.<sup>7</sup>

Age is not the only risk factor of note. As there is significant variation in the prevalence of ophthalmic diseases (including AMD and DR) between populations of different ethnicities,<sup>8-17</sup> and as the ethnic make-up of the UK is expected to change substantially over the next 20 years,<sup>18</sup> it is also necessary to take this shift into account.

## How much more demand is there going to be for our AMD services?

There are various caveats that have to be put around predictions of the future demand on ophthalmic services that will be posed by AMD. Enormous potential variation in the actual demand could be produced by new interventions for prevention or treatment of AMD, which may require more or less intensive clinical management than the current regimes. More efficient methods of delivering treatments would be hugely beneficial and although an evidence base is growing,<sup>19-21</sup> quantification of “real world” intervention burdens and the impact on visual morbidity with the current and emerging intravitreal injection treatment modality alternatives is as yet not clear.<sup>22</sup>

Predictions of the demand put on support services by visual loss from AMD are equally fraught with uncertainties due to lack of data around societal costs of blindness and the long term efficacy of present and future treatments,<sup>23-27</sup> although published epidemiological models predict that the negative effects of demographic shifts will outweigh the positive effects of the new therapies, despite their great efficacy.<sup>28</sup> Helpful studies have been done to provide baseline prevalence prior to the inception of publicly funded treatments targeting vascular endothelial growth factor (anti-VEGF); thus, some indication of the impact of treatment compared to the natural history<sup>29,30</sup> on the burden of blindness at a population level can be gleaned from certification rates, although this data has significant limitations.<sup>31-35</sup>

It is generally accepted that treatment uptake for neovascular AMD (nAMD) is high and default (non-attendance (DNA)) is very low. Although we cannot claim certainty about how prevalence will convert into demand on services, we can apply prevalence data from population based surveys to age, gender<sup>36,37</sup> and ethnicity stratified population projections to give an indication of the future numbers of patients with different manifestations of AMD.

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**AMD case numbers are predicted to rise by nearly 60% in the next 20 years (30% in the next 10 years)**

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It is clear that AMD has been increasing in prevalence in the UK for more than 60 years,<sup>38</sup> and estimates of the global burden of disease predict a rise of 47% between 2020 and 2040 in numbers of people affected.<sup>9</sup>

For The Way Forward project, the National Eye Health Epidemiological Model (NEHEM) was utilised with gender-specific<sup>32,39</sup> ethnographically stratified population projections put into this model at various time points to give estimates of future AMD case numbers. The population projections, AMD epidemiological modelling and discussion thereof are presented in full in appendix B.

The key messages from these Way Forward projections up to the year 2035 are in the percentage increase in the number of people with disease (see appendix B for case definitions and full tables):



- **Neo-vascular AMD (nAMD)** cases is predicted to rise by 59% from 2015 to 2035 (29% rise from 2015-2025) with the prevalence in the population over 50 rising from 1.85% in 2015 to 2.36% in 2035 as the number of elderly rises.



- **Geographic atrophy (GA)** cases is predicted to increase by 58% from 2015 to 2035 (29% from 2015-2025).



- A 40% rise in the number of people with **‘soft’ macular drusen** is predicted from 2015 to 2035 such that the total number would be 3.8 million people, representing 12.9% of those over the age of 50.

This increase in numbers with GA and macular drusen is not presently of great relevance to ophthalmic service demand, but is an area of enormous risk to our capacity should new therapies come on-line, particularly if they involve frequently repeated intra-vitreous injections.

These figures resonate with other published predictions, such as one study published in 2012 predicted a growth by a third in the numbers of patients with nAMD by the year 2020.<sup>32</sup>

If the number of people with GA or nAMD rises by nearly 30% from the current baseline<sup>40</sup> in the next 10 years, and up to 60% growth in the next 20 years, this is clearly going to stretch both ophthalmic services and the support structures that exist to help those with visual loss. Inaction, therefore, is not an option. Changes to the way we deliver AMD services are inevitable as we are not expecting a 60% rise in the number of consultant ophthalmologists in the next 20 years.

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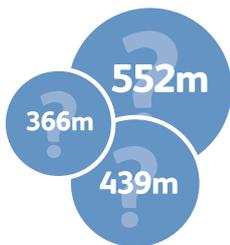
***From 2010 to 2035, the population over 75 years of age is predicted to rise by >80%. Those over 85 will more than double***

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## Diabetic retinopathy Projections for the UK 2015–2035

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The growth in diabetes globally has led to it being commonly referred to as an epidemic.<sup>41,42</sup> Estimates exist for the global diabetic population but these vary enormously. The total diabetic population in 2030 has been predicted to rise to 366 million in one study,<sup>43</sup> to 439 million in another<sup>44</sup> and to 552 million in a third.<sup>42</sup> This variation demonstrates the difficulty in making these estimates. The UK will be protected from some, but not all, of that global rise as developing countries are expected to see the worst of the increase.<sup>45</sup>



### **Projected growth in the diabetic population**

UK estimates of the diabetic population increase are similarly variable, with type 2 DM predominant at over 90% of the total,<sup>46,47</sup> the growth rate in the diabetic population for the UK has been predicted to be between 1.0 - 4.1% annually,<sup>48,49</sup> The lower estimates tend to come from work that assumes that there will be a constant age-stratified prevalence of diabetes,<sup>50</sup> an assumption which has been shown not to be true given the rise in obesity, a major risk factor for diabetes.<sup>51,52</sup>

Projections exist for other countries similar to the UK. For the USA, a rise of 86% is predicted for the diabetic population between 2009 and 2034 (23.7 million to 44.1 million), and the expenditure on diabetes and its complications is anticipated to rise threefold from \$113 billion to \$336 billion annually.<sup>53</sup> In Germany, the prediction is for a 58% rise in type 2 diabetics from 5 million (2.8 million diagnosed) in 2010 to 7.9 million (4.6 million diagnosed) in 2037 (64% rise in diagnosed cases).<sup>54</sup> The conversion from diabetes to DR may not be evenly spread in different health systems; NHS has been reported to out-perform other European nations in preventing complications of DM, although the performance is still described as “poor”.<sup>55</sup>

If the best predictor of future behaviour is past behaviour, then we can draw little comfort from the observation that diabetes prevalence in the UK increased from 2.8% in 1996 to 4.3% in 2005 - a more than 50% increase in 10 years,<sup>51</sup> and glycaemic control was not improving, especially amongst the young. As such, retinopathy rates can

be expected to mirror this rise in diabetes.<sup>56</sup> With predictions about the numbers with diabetes being so uncertain, it is no surprise that there is similar uncertainty about retinopathy rates as the incidence and prevalence of vision related diabetic complications are not well characterised at a population level.<sup>57-61</sup>

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***Prevalence of diabetes in the UK increased by >50% in 10 years from 1996 to 2005***

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## Projected growth in population with DR and demand on eye services

Given the complexities of projecting estimates of the burden on our services due to DR in the future as outlined above, and the additional uncertainties regarding trends in risk factors for retinopathy progression such as glycaemic and hypertensive control, estimates must be viewed cautiously. Obesity, which is reported to cost the UK more than we spend on the police and fire service combined,<sup>62</sup> is predicted to increase rapidly with 11 million more adults in the UK projected to be obese by 2030 compared to 2010. There is, therefore, considerable medical and political interest in the development of effective interventions for this.<sup>52</sup>

Novel therapies either for retinopathy,<sup>63</sup> diabetes itself or the risk factors for diabetes may entirely change the situation. Technology has already had a significant impact on the burden of work in screening for retinopathy both for data acquisition and interpretation, and this impact is only likely to increase, as exemplified by the automated grading of retinopathy<sup>64-67</sup> and the possibility of reliable retinal imaging and visual acuity measurement by smart phone.<sup>68,69</sup>

In summary, the population with DR is expected to increase by at least 20% over the next 20 years if age specific prevalence remains constant.<sup>50</sup> However, as this seems highly unlikely, the true figure is likely to be closer to the 50-80% rise predicted for other western countries.

***An increase in the Diabetic population of the UK and the associated rise in DR is estimated at between 20-80% over the next 20 years***

For the purposes of discussion for this Way Forward Project, we can consider that the rise in the burden of diabetic retinopathy from the current baseline<sup>70,71</sup> between 2015 and 2035 will be similar to that expected for AMD (ie ~60%). Even if armed with this estimate (of percentage growth in the numbers of patients developing retinopathy), the translation of this into demand on services is very much altered by the delay to diagnosis, the treatments available to us, the modes of delivery of these treatments, as well as the uptake of services, which is affected by socio-economic status and age of the

patients amongst other things.<sup>14,72-78</sup> If more treatments become available (surgical or medical), and are deemed sufficiently cost-effective to be made available on the NHS, then indication expansion will create a growth in demand, although better treatments of diabetes or its complications may equally reduce the burden on services.<sup>79-82</sup>

## So what? Applying these estimates to your Medical Retina service

One consultant interviewed for this project was asked about their hospital eye department's plans for the increasing numbers commented, *"we don't plan for growth, but just for what is currently required. We know a wave of patients is going to hit us, but nothing is done, until there is a large backlog, adverse outcomes, patient complaints - and only then, is there enough of a driver for the managers to expand capacity - but as the service grows - the cycle repeats itself. Proactive planning is needed rather than just responding to serious untoward incidents (SUI)."* (AMD27) If we fail to plan, we are planning to fail.<sup>83</sup>

Predictions of the expected growth in DR and AMD patients permit us to sit down with hospital managers locally and open discussions about how services need to be changed now in order to cope with a rise in demand on the service of around 60% over the next twenty years, rather than waiting for patient complaints to spur us into action.

***Proactive planning is needed rather than just responding to serious untoward incidents***

Between June 2005 and May 2009, the National Patient Safety Agency (NPSA) received reports of 44 glaucoma patients who experienced deterioration of vision, including 13 reports of total loss of vision, attributed to delayed follow up appointments.<sup>84</sup> Medical Retinal services are under the same pressures and risks of delayed follow up. A British Ophthalmic Surveillance Unit (BOSU) study is soon to report on this same issue, and the results are expected to resonate with the NPSA findings. In response, the RCOphth has published a Three Step Plan for eye departments to implement in order to protect patients from the negative consequences of the delays caused by the rapid growth in demand, cited as 40% increase in outpatient activity in the past 10 years.<sup>85</sup>

It is therefore incumbent upon us, as clinical leaders in our Medical Retina services, to explore options to meet both the current challenge and the anticipated further increase in demand. A wider discussion of the interaction between demand and capacity in service planning is detailed in appendix C, and practical options for AMD and DR services configuration are presented below.

The relative benefits and cost-effectiveness of different therapies for the treatment of AMD and DR has been widely discussed in the peer reviewed literature and is beyond the remit of this report,<sup>86-101</sup> but it should be emphasised that the financing of public healthcare is a zero sum game and as such, every pound spent on one area is a pound not available to deliver other services. The drive towards lower-cost delivery of eye care must therefore be seen as aspirational, minimising the unstructured but inherent rationing caused by perpetuation of sub-prime practices.

## Role of eye care professionals and hospital eye departments in prevention of AMD and DR

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### Is prevention possible? Modifying risk factors other than age

Faced with the prospect of having to cater for this level of increased demand, the question has to be asked whether primary or secondary prevention is possible, and what role ophthalmologists might take in this.

#### AMD prevention



##### Smoking

Smokers have been shown to be more than twice as likely to have nAMD and more than 4 times more likely to have GA.<sup>102,103</sup> This should encourage propagation of health education messages around stopping smoking and promoting access to cessation services within our own departments.<sup>104</sup> A survey looking into the advice given to patients with AMD by eye healthcare professionals found good awareness of nutritional issues in prevention, but less widespread dissemination of smoking cessation messages.<sup>105</sup>



##### Cardiovascular risk

Cardiovascular risk factors and poor diet have been shown prospectively to be associated with increased risk of developing AMD in an 18 year follow-up of a cohort of 2,348 men from Bristol,<sup>106</sup> although, as the authors comment, this does not mean that treating risk factors or promotion of exercise<sup>107</sup> will reduce the burden of AMD visual loss as people will then live longer. Nonetheless, dissemination of evidence-based dietary advice<sup>108-110</sup> and other measures to reduce exposure to known risk factors is a potential preventative role that ophthalmologists could take on.

Fear of sight loss is often reported as a major anxiety that people have about both diabetes and older age, and it may be appropriate for this to be leveraged in encouraging lifestyle changes in eye clinics at the point of detection of early disease or in those at risk of starting smoking.<sup>111-113</sup> Such health promotion messages most need to be heard by those living in less affluent areas who may be more resistant to health promotion interventions.<sup>39,114</sup>



##### Family members

Although early detection is not primary prevention, the demonstrated increased risk of siblings of affected individuals (adjusted odds ratio of 16) compared to spouses,<sup>115</sup> as would be expected from the genetic influence inferred from twin studies,<sup>116</sup> suggests that warning those with a family history of nAMD about the symptoms should promote lifestyle changes and provoke acute presentation.



### Nutrition and supplements

The issue of nutritional supplements used in the prevention of AMD, although shown to be beneficial by the Age-Related Eye Diseases Study (AREDS), has not as yet been taken on as a publicly funded large-scale intervention in the UK. The cost-effectiveness of prescribing AREDS supplements compared to patients not taking them at all might be expected to be good.

## DR Prevention: combining general diabetic care with diabetic eye care



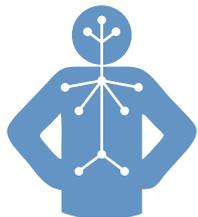
### Tighter glycaemic control

Since the Diabetes Control and Complications Trial (DCCT) and the UK Prospective Diabetes Study (UKPDS) reported, there is a clear mandate to encourage diabetic patients to strive for tighter glycaemic control. This can be captured in the aphorism that every percentage point reduction in HbA1c conveys a 30-40% reduction in risk of retinopathy.<sup>117</sup> Risk factors for rapid progression such as sudden tightening of glycaemic control at diagnosis or in pregnancy are recognised and specific pathways for such, (eg pregnant diabetic service) to mitigate risks are reported (*DM10*).



### Blood pressure

Blood pressure control is equally well established as a means by which patients can reduce their risk of developing and worsening of retinopathy, with the tight control group in UKPDS having a one third less retinopathy than their less well controlled counterparts. This protective effect is amplified if angiotensin converting enzyme (ACE) inhibitors are used, a protective effect that surpasses the protection conveyed merely by the hypotensive effects of the medication.<sup>118-121</sup>



### Systemic factors

Other systemic factors interact with the progression of retinopathy. Control of hyperlipidaemia in diabetics with fenofibrate has been shown in the FIELD study to be beneficial for retinopathy (>30% less need for laser for both proliferative disease and maculopathy over 5 years).<sup>122</sup> As with ACE inhibition, the effect of this medication may surpass the benefit conveyed directly by alteration of the lipid profile and it may be justifiable to prescribe for any diabetic with retinopathy.<sup>123,124</sup> Conversely, pioglitazone has been associated with worsening or refractory maculopathy and its cessation may be advocated in patients with refractory maculopathy.<sup>125</sup>

### Role of the eye clinic in prevention

These above facts are well known,<sup>126</sup> however the role of the ophthalmologist or the eye clinic in promoting BP and glycaemic control is less well established. It can be argued that the diabetics attending our clinics are all, by virtue of their presence there, inherently relatively engaged and in touch with services compared to those who are failing to attend. It might also be reasonable, in response to the existent capacity issues, to focus on their eye care as this is the primary role of the diabetic eye clinic. However, it has to be acknowledged that an opportunity exists to go beyond eye care.

One consultant reports having a successful diabetic foot service running alongside their eye clinic for many years, minimising the burdensome number of appointments diabetic patients have each year (*DM 36*). Data from a departmental pilot study of a Diabetic Specialist nurse service seeing every new DRS referral alongside the ophthalmology clinic was shared. Of 73 patients seen in the pilot, about half needed their diabetic medication changed and 10% were referred on to an endocrinologist (*DM 11*).

Other consultants reported taking an active approach to contacting GP, referring to diabetic physicians or community diabetic nurses when patients, particularly with progressive retinopathy were found to be sub-optimally managed for their general diabetes (*DM 12, DM 25*).

- Not many units have the space or capacity to run general medical diabetic clinics alongside eye departments, but opportunities for joint working or streamlined referral to appropriate services such as diabetic nurses or foot clinic could be sought possibly in a community setting

Patient education provides multiple benefits for patients and eye care services by reducing “Did Not Attend” (DNA) rates and encouraging ownership of glycaemic and hypertensive control<sup>127</sup>

- The minimum intervention should be to communicate with whichever clinician (GP or diabetologist) is coordinating the patient’s diabetic care, to inform them about progressive disease and to encourage optimisation of medical management
- The utility of taking one-off readings of BP, blood lipids or HbA1c in the context of the eye clinic as a screening tool has not been established, and few, if any, ophthalmologists would feel it appropriate for them to alter medication prescribed for diabetes. It may be, however, inexpensive and achievable for clinic staff to gather tick-box data to allow some comment on systemic management to be made in their GP letter

### Prevention summary

Although no examples were identified of health promotion messages reducing the risk of visual loss specifically, in view of the ~60% rise in AMD and DR expected over the next 20 years, attempts at up-stream thinking to reduce the numbers of patients needing our eye services should be encouraged. The burden of AMD and diabetes on individuals, their caregivers<sup>128</sup> and society in terms of reduced quality of life and requirement for daily living assistance is an important social and economic consideration.<sup>25,50,53,54</sup> The voices of ophthalmologists should be heard promoting potential avenues for prevention, and research into these options should be encouraged.

## Referral Management

Referral of patients with suspected neovascular AMD (nAMD) needs to be efficient and rapid as there is only a small window for effective treatment. Many departments have arrangements with primary care for a fast track referral pathways based on history and examination although some community optometrists use OCT imaging to evaluate patients. This can reduce referral rates for false positives but can also be a source of unnecessary referrals due to difficulty in interpreting results of the scans.

### Traditional Pathways for AMD and DR clinics

The traditional service configuration for the delivery of eyecare is well known (figure 1). Referral letters are triaged, the patients seen in clinic, investigated, treated and followed up; all done by ophthalmologists.

All parts of this pathway have been explored for opportunities to identify how to optimise the resources available, particularly with reference to best utilisation of the limited time and availability of consultant ophthalmologists.

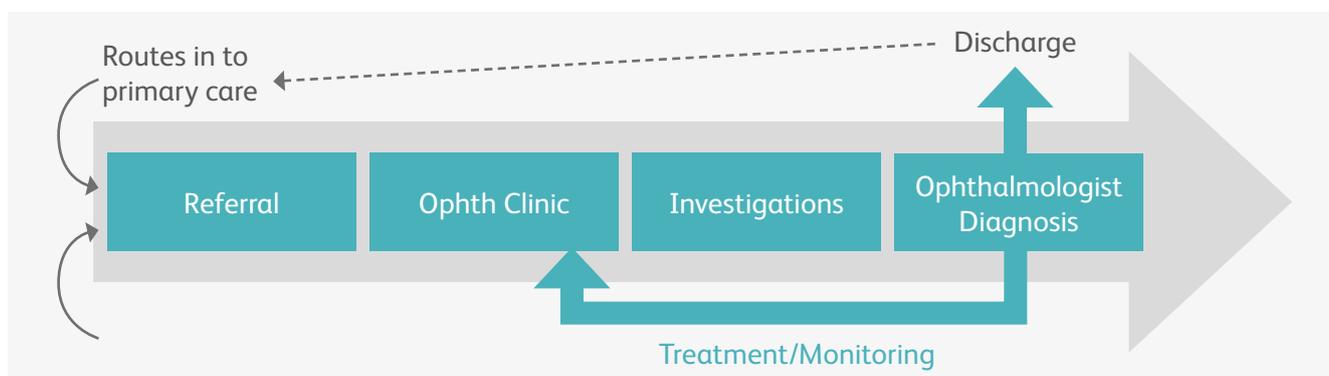


Figure 1: Traditional pathway for ophthalmic patients attending AMD or Diabetic retinopathy clinics

# Management and flow of patients with nAMD

Following referral, urgent assessment is required to confirm, or refute, the diagnosis of nAMD so that treatment can be commenced rapidly. Imaging is an essential part of this process, and reviewing and making clinical decisions on these images are being carried out by various members of the team in different locations (figure 2 and see virtual clinics below). Treatment and further assessment are carried out by medical staff or nurse injectors at one stop, two stop or multiple stop clinics – depending on preference, availability of trained staff and local geographical circumstances.

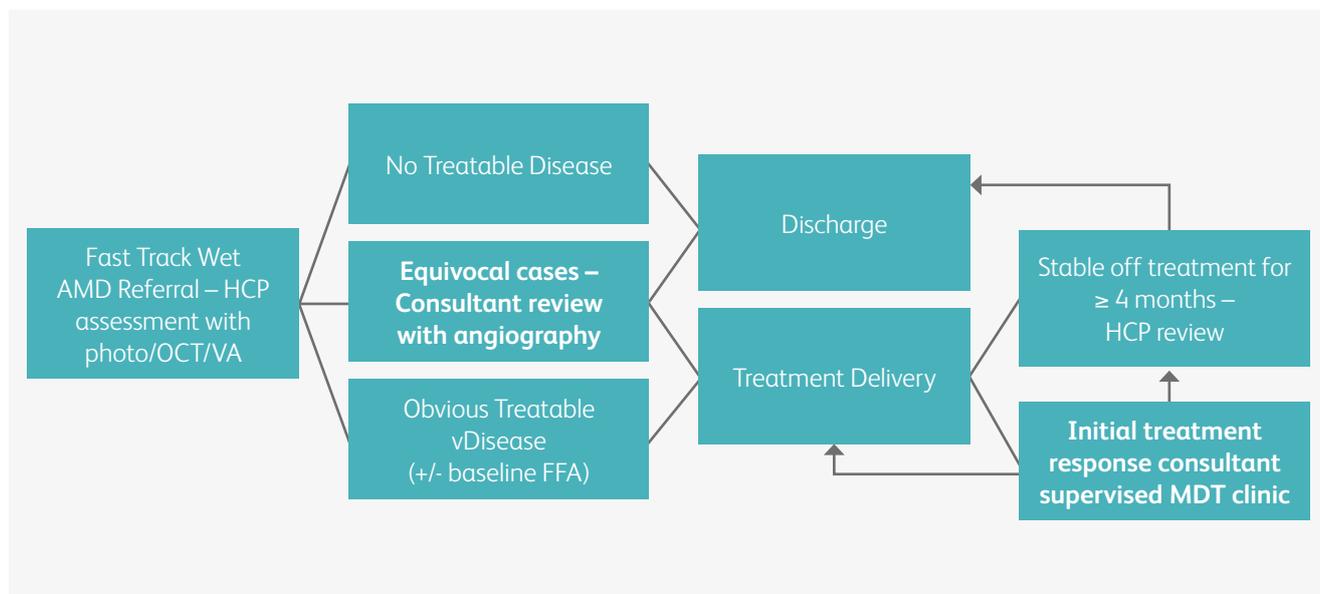


Figure 2: Referral and flow through hospital system with early triage and focused treatment delivery

## Action on AMD

The Action on AMD group published a report covering similar ground to the Way Forward which was endorsed by the RCOphth.<sup>129</sup> The primary conclusion of this work was that *“robust and long-term retinal service models must be rolled out in order to meet the needs of local populations both now and in the future. Action on AMD strongly advises that every hospital with a retinal service start this process now.”*<sup>130</sup>

***“robust and long-term retinal service models must be rolled out in order to meet the needs of local populations”***

Five key capacity limiting issues, the consequences of deficits and possible solutions in each area were identified. Departments are advised to analyse which of these limitations are currently creating the bottlenecks on expansion of capacity in their current services (figure 4). The need for urgent proactive consideration of future capacity planning cannot be over-emphasised. The lead time on capacity expansion makes reactive management of capacity deficits an unattractive option.

Various clinical pathways and service delivery models were presented in the Action on AMD report which merit consideration individually, but the unifying feature is a commitment to optimising utilisation of the consultant ophthalmologist resource, demonstrated in figure 2.

|                               | Issue  | Consequences and solutions   |
|-------------------------------|--|--|
| <b>Clinic Space</b>           | Limited space can prevent patient-centred one-stop service development                         | Re-locating parts of the pathway to <b>mobile</b> or <b>community</b> facilities, or creation of <b>virtual clinics</b> can help this  |
| <b>Staffing</b>               | Shortage of MR consultants or other senior ophthalmologists                                    | Where the bottleneck is for consultant review, all non-consultant dependant tasks <b>must be devolved to HCPs</b>  |
|                               | Administrative staff shortages   | Loss of capacity due to inefficiency in booking and clinical risks with appointment mismanagement  |
|                               | Limited appropriately skilled HCP  | This creates inability to task-shift from consultants to HCPs, but can be helped by ensuring <b>all staff are operating at the top of their licence</b> freeing up more senior HCP to take on advanced roles |
| <b>Equipment</b>              | Insufficient access to OCT or angiography  | <b>Virtual clinics</b> permit divorce of image acquisition from main clinic times easing bottleneck but risking patient inconvenience if multiple visits needed  |
| <b>Support and monitoring</b> | Weak support services for patients (LVA, ECLO) or clinicians to record data for audit          | <b>Electronic patient records</b> circumvent problems collating information for audit of clinical outcomes for quality assurance and feedback to commissioners   |
| <b>Funding</b>                | Unsuccessful or short-term focussed business plans lead to failure to build long-term capacity | Lack of expansion possibilities for human resource or infrastructure. Need to <b>“invest to save”</b>  |

Figure 3: Various key capacity issues create different limitations to AMD service capacity

From – Amoaku W, Blakeney S, Freeman M, et al. Action on AMD. Optimising patient management: act now to ensure current and continual delivery of best possible patient care. Eye 2012; 26 Suppl 1: S2-21.

## Virtual Clinics



Virtual AMD clinics were being run in 63% of eye departments (17/27). Virtual clinic models differed in their construction.

**Virtual for new patients transitioned into HCP clinic** – VA, OCT and colour photos permit virtual assessment of new referrals in one department which included ophthalmic ophthalmic healthcare science practitioners in clinical decision making. After initial review of 100% of cases by consultant ophthalmologists, this regime was then relaxed to review selected cases at a weekly meeting for 3 years. Now, review of cases is initiated by the practitioners who have easy access to consultant if needed (AMD 18).

**Virtual just for stable off treatment** – One department set up a virtual review system with photos and OCT taken for patients who had required no treatment for 3 months or more, and these are reviewed by a consultant; this virtual service is also used to review patients at the end of their 3 injection loading phase for treat and extend (AMD 21).

**Virtual follow up clinic transitioned naturally into HCP clinic** – A department running PRN injections for ranibizumab (Lucentis) and treat and extend for aflibercept (Eylea) moved patients into a virtual clinic with orthoptists performing VA, OCT and colour photographs after 6 months of stability with no treatment. Initially the orthoptists made clinical recommendations that required review by an ophthalmologist, but after audit of these initial recommendations they were then signed off such that review of their decisions is only undertaken on request. Patients are then discharged at 12 months (AMD 26).

| Virtual Clinic   | Virtual with HCP Input  | Autonomous HCP Clinic   | HCP Virtual Clinic  |
|--|---|---|---|
| Images acquired by HCP reviewed by consultant for treatment decision | HCPs acquire images, evaluate and propose treatment plan, confirmed by consultant | HCP clinics with access to consultant support if needed. Quality assurance by audit or review of a sample | Technicians acquire images for HCP review, with consultant input on request |

Figure 4: Evolving efficiency: virtual clinics can morph into non-medical HCP clinics, which can then morph into non-medical HCP virtual clinics to expand departmental capacity

**Virtually Supervised HCP Clinics: a stepping stone to decentralising AMD clinics** – Virtual clinics may be set up to involve HCPs in image assessment. Images graded by HCP can be pulled and reviewed for quality assurance purposes.. A service using optometrists to assess images and nurses to deliver injections is used to permit a one-stop shared care service to be run in various community settings including mobile facilities. The acquired images are available to view at the base hospital so the supervising consultant can review and give input as necessary. This does require IT networking but is appreciated by elderly visually impaired patients (AMD 17).

**Virtual Pressure Valve** – Some reported only switching to virtual clinics when a backlog builds up (AMD 16), or when a consultant is on leave (AMD 13) or there is a staff shortage (AMD 12). If a service is struggling for capacity, rather than putting on extra weekend and evening clinics, consultants could be paid on a “per case” basis to review images and make decisions to generate extra capacity that is more convenient than out-of-hours services (AMD 13).

Concern about virtual services for AMD was expressed in that they are best suited to relatively “homogenous patient groups” but AMD management has a bespoke nature for each patient that makes it hard to retain maximum quality when moving into one-stop virtual services with injection and imaging (AMD 13). However the efficiencies that virtual services can bring may protect patients from prolonged delays.

### Optimising effectiveness in virtual services

The most efficient models have every task done by an appropriate team member, so all are working at the top of their grade. This is particularly relevant and important for ophthalmologists who undergo extensive and comprehensive training over several years during which they accumulate a wealth of experience. This training and experience is invaluable in order to elicit and interpret clinical findings and to make robust and effective decisions. Consultant time is therefore precious and for consultants to be operating at the top of their grade requires careful devolution of tasks that can be performed by others.

There are many options and variations and it may not be possible to create the perfect system for each locale immediately. Starting with consultants grading every image, and relatively senior HCP staff being trained to acquire images may be what is needed at inception, but as figure 3 shows, a sequential shift down of tasks can then follow so that a Band 5 nurse seldom checks someone’s visual acuity or a consultant does not do an injection.

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*One example was a clinic where a band 2 clinical support worker checks the vision, a band 2 technician captures the images with some band 3 technicians providing oversight and running the Quality Assurance processes for data acquisition; appropriately experienced optometrists are brought in to do the virtual review of these images with a consultant double grading 100% of their images in the first week, 50% of images in the next month and then as requested thereafter (AMD 7)*

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## Review of Virtual Images

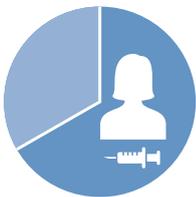
IT provision is a determinant of a department's ability to provide virtual services. Electronic patient records, standardised letters going out to patients/GP and rapid image handling all make a virtual clinic a time-efficient model.



The number of images that one consultant can review in a 4 hour session were typically reported at 30-35 (AMD 9, 7, DM 16). Comment was made that concentration over a full dedicated 4 hour virtual review session was not easy, such that as with glaucoma virtual clinics, the strong tendency is to **break this work up into 30-60 minute chunks**, which are more digestible and can be fitted around the working day rather than done en-bloc.

The ease with which virtual review can be double graded or a second opinion sought makes routine virtual review an ideal target for task shifting away from consultants' job plans where appropriately trained and competent HCPs can be recruited.

## Non-medical HCP Injectors



Around two thirds of departments interviewed had non-medical eye HCPs performing intra-vitreous injections (18/28), whilst the remaining 10/28 had only doctors involved in such procedures. One consultant commented from a tax-payers perspective, paying a consultant salary for someone to give routine, regular intravitreal injections is not justifiable, and it is an activity of very little training benefit for Specialty Trainees. Making the clinical decisions about injections, and overseeing a complete medical retina service is, however, a high value activity that properly utilises the years of training and experience that creates a senior ophthalmologist.

The barriers to moving to non-ophthalmologist injectors varied. Difficulty recruiting for extended roles was mentioned and one consultant reported having advertised three times for someone to take on an injector role, but had no applicants (AMD 13). Difficulties in backfilling posts in order to release staff into an extended role was also described (AMD 29), as was anxiety amongst senior nurse managers about "who is taking responsibility" which led them to block the appointment of nurse injectors (DM 28).

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### *Difficulty recruiting for extended roles*

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Eye departments in which only doctors gave intravitreal injections were not the smaller units as might be expected, and whilst some reluctance to change is inherent in the NHS, and being risk-averse is largely appropriate, the case for non-ophthalmologist injectors has been clearly made, and training and medico-legal considerations explored and an excellent safety profile established.<sup>131-137</sup>

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### *The case for non-ophthalmologist injectors has been clearly made, training and medico-legal considerations explored and an excellent safety profile established*

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Training courses for non-medical HCP injectors do exist, and the path to follow is now clear and well-trodden. However, some consultants consider that they have the capacity to see patients and undertake intravitreal injections at the same clinic. The choice is up to local Trusts as to how to deliver efficient and cost-effective services.

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*From a tax-payers perspective, paying a consultant salary for someone to give routine intravitreal injections is not justifiable... Overseeing a complete medical retina service, however, properly utilises the years of training and experience that creates a senior ophthalmologist*

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## One-Stop clinics for intra-vitreous injections

For new referrals with potential nAMD, 30% (8/27) of consultants had managed to configure their service so that most patients could be assessed, investigated and treated in one initial visit.

One stop clinics are not easier to run, they do not make more money or help with space issues, but they are more efficient for elderly patients, the environment and many of the indirect costs of a macular service. Many consultants who have made this system work were proud and cited this when asked to name the “best part” of their service (AMD 4,7,21,29,30).

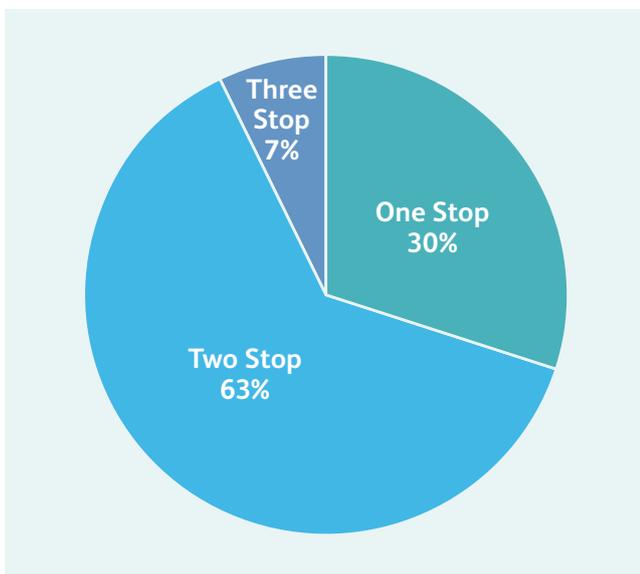


Figure 5: New AMD Referrals: 1-2-3 stops

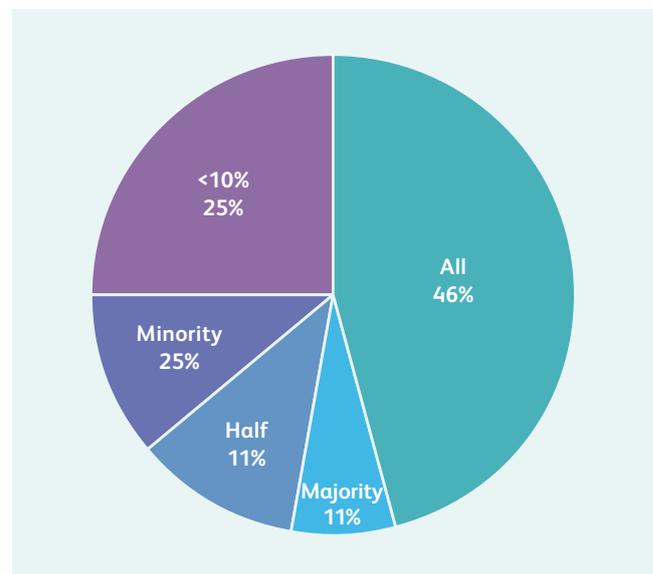


Figure 6: Percentage “one stop” follow up AMD clinics

There are good reasons why this one-stop clinic set up has not been established in many areas; one consultant lacking physical space to run injection lists at the same time as clinical assessments commented that “*even a taxi driver asked why we don’t do injections on the same day as clinic as he had brought the same patient back and forth several times*” (AMD15). To save on visits without a one-stop set up, one consultant earmarks patients who are felt to be very unlikely to respond to a single intra-vitreous (i.e. patients presumed to require 2 or more consecutive injections), and books then in for a series of 2 or 3 injections without any review or imaging in between, which saves on capacity (DM 9).

The majority (63%) 17/27 had patients attend an assessment/investigation clinic then brought back patients for a separate injection list. Two departments (7%) require patients to attend for investigations separate from the face to face assessment and then a third visit for injection (figure 5). For AMD follow ups (figure 6), many more departments had configured a one-stop service, but a quarter of them had more than 90% of their patients coming back separately for investigations or injections.

For diabetic clinics, the split was even with 14/30 offering one stop assessment and injection clinics for those on the DMO injection pathway, and 15/30 requiring patients to come on a separate occasion for their injection if deemed necessary at the assessment clinic.

Unpicking the drivers and barriers for the creation of a one-stop service is not easy. There is a general acquiescence in the perception that one-stop services are more patient orientated, but logistical considerations make two stop services easier to run, especially for those running separate injection-only lists.

| Against One-Stop services  | For One-Stop Services   |
|--|---|
| Patient uncertainty creates anxiety: “Will I or won’t I need an injection?”  | Reduces the fixed “per-visit” costs to the department in use of support staff (eg admin pulling notes, booking in etc.) |
| Inevitable variation in the number of injections being required can waste capacity – injector standing idle at times | Reduces transport costs, patient & carer opportunity costs & environmental impact                                       |
| Two stop service can permit the creation of efficient high volume injection lists                                    | Can be adapted to virtual “treat and extend” clinics  |

Figure 7: Pros and cons of one stop services

Whilst services were largely configured in this binary fashion, either one-stop or two-stop, attempts to get the best of both worlds were described where injection lists were running alongside assessment clinics. Some injection-only (e.g. loading phase) patients are booked at the start of the clinic so there is no downtime for the injection room at that point, but enough capacity is left to accommodate most of the patients that are fed through for injections. This requires some knowledge of what proportion of patients in a clinic typically are deemed to require injections. Thus an efficient dedicated injection list can be run alongside assessment clinics. The clinic numbers need to be set such that even if less than average injections are required, the injection capacity is still adequately utilised. If the more than the average numbers of patients require injections on the day, then there may be the requirement to bring some people back to a subsequent injection list.

For example, if an assessment clinic booked with 24 patients found to typically yield 12-18 injections is run alongside an injection list with capacity for 16 injections, and the first 4 slots are booked for injection-only patients, there is very little chance of wasting capacity. However, between 0 and 8 patients (average 4) will need to come back for a separate injection visit, unless extra injection capacity can be created on the day.

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**Assessment clinic booked (24 patients) typically yields 12-18 injections**

- **First 4 injection slots pre-booked to avoid wasted capacity at start of clinic**
- **16 Injections slots fully utilised**
- **Average of 4 patients who don’t get 1 stop service**

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## Intravitreal injection service management

The number of intravitreal injections a Medical Retina service needs to provide varies with the particular treatment regime adopted for maintenance, be it PRN with fixed monitoring intervals, ‘monitor and extend’, ‘treat and extend’, or fixed dosing, rather than the particular anti-VEGF drug (of those currently available).

The number of intravitreal injections departments are expected to deliver is rising with each passing year, and maximising throughput whilst maintaining the quality and safety is essential. One consultant reported giving 500 intravitreal injections in their first year of running this service, 1,000 in the second, 2,000 in the third and 3,000 in the fourth (DM 23). The ability to grow staff numbers at that pace is a challenge, and growing space capacity (accommodation) for the service is usually more problematic; hence, streamlining injection service processes is going to be desirable

| Injections Per list | ≤10 | 11-15 | 16-20 | 21-30 | 31-40 |
|---------------------|-----|-------|-------|-------|-------|
| Doctor              | 0   | 9     | 10    | 1     | 0     |
| HCP                 | 3   | 5     | 5     | 1     | 1     |

Figure 8: Number of departments providing different numbers of injections / 4 hour list

Figure 8 shows the spread of practice across departments surveyed for their injection services. Conditions that dictated productivity varied with some having physical environments that facilitated higher throughput, but processes and personnel must account for more of the variation seen.

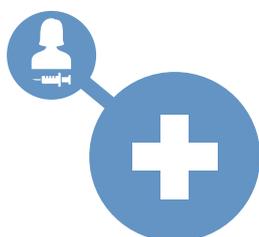
- Two separate rooms: with a scrub nurse in each room preparing and a clinical support worker bringing patients in and out, the injector can move from one room to the other achieving 20 injections per 4 hour list (AMD 14)
- One room with partition wall separating 2 beds permits 20 injections to be done per session (AMD 9)
- The highest throughput was achieved by enthusiastic staff such that one nurse injector (supported by a healthcare assistant) could perform up to 40 injections per session (AMD 18)
- A multi-disciplinary team reports efficiently running a large one-stop service with nurse injectors augmented by flexible working from optometrists and doctors doing assessments, who are also able to start delivering injections if pressure builds up on that aspect of the clinical load during a session; hence 30 injections are given in one session alongside the assessment clinic (AMD 21)
- Mobile intra-vitreous injection unit. Lack of space is often a problem and a dedicated mobile unit can increase capacity and deliver care closer to home

The numbers in figure 8 hide a great deal of heterogeneity in what is actually being done; the higher volumes being achieved by well supported injectors whose sole function is to deliver safe injections either as part of an MDT delivered one stop service or as a standalone injection clinic, which then necessitates repeat patient visits.

Reflecting on the spread of numbers from across different units, one consultant commented, “*In our ‘treat & extend’ regimen a single doctor has to review the OCT for each patient, determine the treatment interval for next injection, document in the notes / EPR / outcome sheet & dictate a letter and then inject... and [it is difficult to] manage 14 injections per 4 hour session*” (AMD 13).

There may be no way this high quality consultant delivered one-stop model can see more than 14 patients per session, but if the ophthalmologist was to be limited to the tasks where they provide the most value (clinical decision making), and the administrative elements and the injection were performed by other multi-disciplinary team members, the capacity of the system could increase...

## HCP injectors in remote centres without an ophthalmologist present



The desire to have non-ophthalmologist injectors working in centres without a doctor on site can spring from the need to minimise travel for elderly patients in low population density areas. It might also arise where non-traditional NHS providers wish to provide low cost injection services away from a hospital setting in higher population density areas. Very careful consideration has to be given to the potential complications of the service being offered and the ability of the staff involved to recognise and deal with those complications when they arise.

Audit data obtained from Eyecare Scotland reported that of 23,572 injections from one health board, 10,359 of which were performed by a nurse practitioner, only one case required urgent medical intervention leading to a paracentesis being performed. Another audit of 2,000 injections from a different health board reported no cases requiring such intervention. The unquantified but very small risks of injecting in a setting remote to the main hospital site have to be balanced against the well-known negative effect of delays to commencement of therapy with anti-VEGF agents. The balance of probability is felt to be clearly in favour of doing everything possible to facilitate prompt treatment, and to that end Eyecare Scotland support the practice of appropriately experienced HCP injectors working in remote facilities without an ophthalmologist

being on site. Protocols for dealing with complications are mandatory in such cases, and provision made for the administration of intra-venous acetazolamide in the event of central artery occlusion being detected (communication from Eyecare Scotland, March 2016).

## Optimising value in the Diabetic Retinopathy Screening (DRS) programme

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The national diabetic retinopathy screening (DRS) programme, started initially in Scotland, was hailed as the first of its kind in the world.<sup>138,139</sup> Since its inception and roll out to the whole UK, the programme has continued to evolve, getting patients referred earlier and producing an impact on blinding retinopathy rates despite the expected problems of uptake and inequity of access.<sup>140-143</sup>

Automated extraction of patients with diabetes from GP registers has been shown to improve coverage.<sup>144</sup> Improved efficiency of the DRS with reduced DNA rates through minimising inconvenience to patients caused by the time, travel and dilation regime, and optimising screening intervals to reflect risk have been researched and debated and can be expected to develop.<sup>139,145-161</sup>

Large scale screening programmes of this nature have to be shown to be cost-effective, and a recent move by the National Screening Committee (NSC) to recommend the screening interval for low risk patients be extended to two years reflects this need.<sup>162</sup> Other opportunities for large scale savings exist in the choice of the number of photos taken. Taking a single photo rather than two photos would halve the number of images needing screened each year and permit the majority of patients to have their images acquired undilated<sup>155</sup> which would be expected to improve the acceptability of screening. The necessity exists to prove that mydriatic multiple images or widefield images are both effective and cost-effective in preventing visual loss as compared to single images (predominantly non-mydriatic) if such practices are to be advocated.<sup>163-165</sup>

### Ophthalmologist involvement in screening programmes

A great deal of attention has been paid to the development of quality assurance in the DRS since its commencement. Good levels of consistency have now been achieved, with the DRS being shown to perform favourably compared to HES or community optometrist grading by biomicroscopy.<sup>166-174</sup>

Where external quality assurance (EQA) has locally shown trained graders to have scores akin to those achieved by the senior ophthalmologists, it may be a reasonable next step to make best use of those ophthalmologists time by focussing their time on the arbitration of complex cases only.

### Automated disease/no-disease grading

A full review of the evidence for interventions to optimise DRS services is beyond the scope of this report. However, the use of automated grading requires flag-posting because of the opportunity it represents to increase capacity within DRS, capacity which could be co-opted into the HES.

As computerised visual recognition software has developed, incorporation of automated grading into the DRS is a potential way of reducing the burden on human graders if it can be done safely.<sup>65,175-177</sup>

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***‘It is impossible to imagine that automated grading will not be rolled out across the UK saving a great deal of capacity in the DRS. This capacity can be put to use in higher value activities such as referral refinement and virtual surveillance clinics’***

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After initial trials, automated “disease/no-disease” grading has now been implemented in all but one of the regions in Scotland for the past 2 years.<sup>178,179</sup> This permits direct comparison of the Scottish system with the rest of the UK. Cost per QALY comparison favours the Scottish model as the Scottish graders have

about one third less images to deal with each year as a result of the automated grading. The computer can grade 600 images per day, and does not object to being part of the 7 day week NHS. The safety profile is excellent as demonstrated by the quality assurance processes applied to manual graders with weekly internal regrading by a Band 3 grader of 12 images, and twice yearly external quality assurance processes run by NHS Scotland's DRS Collaborative.<sup>66,67,180</sup>

It is impossible to imagine that automated grading will not be rolled out across the UK, improving capacity in the DRS. This capacity can be put to use in higher value activities such as referral refinement and monitoring of DR as will be described below.<sup>174</sup> Attempts to create automated detection of proliferative disease have been made, but with the penalties for missed cases being high, this may not prove so easy to implement. As such, it may be that incorporating treated proliferative disease into the manual screening service comes as a first step.<sup>181,182</sup>

## Referral Management

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In any pathway, there is going to be a false positive referral rate, and where the consequences of failure to pick up disease at an early stage can be serious, such as in nAMD or proliferative DR, some degree of specificity may need to be sacrificed for the sake of maximising sensitivity.

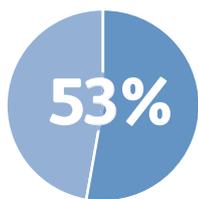
### Referable Diabetic Maculopathy: Referral Refinement

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*Over half of diabetic referrals to HES might be considered false positives and thereby form an attractive target for demand reduction*

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Typically, about 75% of referrals to the HES from the DRS are made for maculopathy.<sup>183</sup> Departmental audits report that of those 75%, **three quarters (thus 75% of 75% = >50% of all referrals) are found not to require intervention and are returned to the DRS** for surveillance or given a hospital follow up appointment of >6 months (*DM 8, 11, 28, 30, 31*). Thus over half of diabetic referrals to HES might be considered false positives and thereby form an attractive target for demand reduction.



At interview, **17/32 (53%) of diabetic eye services reported that virtual review of referable maculopathy was being undertaken** (figure 9), and published examples exist of the use of OCT and images to identify eyes without significant disease.<sup>184,185</sup> This referral refinement could be conducted within the DRS programme itself.

Many screening programmes have recognised the excessive burden of low risk maculopathy referral on their HES and have set up refinement processes that utilise their own screeners. The use of OCT for this purpose within screening programmes is supported by a recent National Institute for Health Research (NIHR) Health Technology Assessment (HTA).<sup>180</sup>

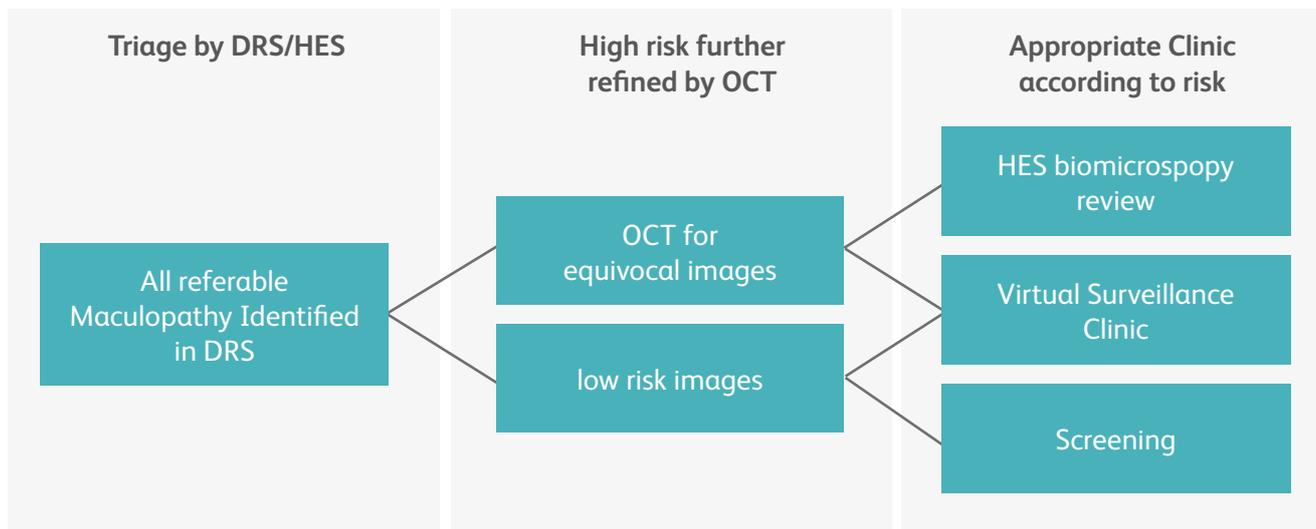


Figure 8: Refinement of diabetic maculopathy referrals could divert over half away from hospital ophthalmology clinics

- Where screeners are not refining the referrals themselves, eye departments can introduce **virtual review of the screened images** that have triggered referral. This may not be possible in England if private companies are running the DRS and the images are therefore not available (in Scotland, SCI-Diabetes acts as a common web portal for primary and secondary care as well as the DRS so that all aspects of eye care are visible for an individual regardless of where these are performed)
- One hospital eye department, unable to view images for this reason, decided to take their own photos and **OCT of referred maculopathy** in order to undertake virtual assessment of these patients (DM 16). In contrast, the departments where the consultant responsible for the HES diabetic eye service is also leading the DRS, or hospital staff also work as screeners, have reported good synergy from the arrangement (DM 4, 18, 25, 28) – emphasising the importance of collaborative working
- Virtual review can be undertaken by the screeners, ophthalmologists or appropriately trained and experienced non-medical HCPs. This permits patients to be allocated to an appropriate service and minimises the number of non-significant maculopathy patients reaching eye clinics

Variations on this referral refinement exist, and include:

- After consultant triage of referral images, low risk cases can be
  - sent to trained community optometrists (DM 3)
  - or put back into the DRS (DM 4)
- Screeners can directly refer obviously significant cases, divert clear low risk cases to surveillance at 6 months and request virtual review only for equivocal images; this reduces the number of images requiring review (DM 11)
- Maculopathy referral refinement by OCT can utilise existing equipment where this exists in community settings (DM 13), or ultra-wide field photos and OCT run by HES can be used to review all referrals<sup>185</sup>
- Community optometrists with training and available equipment (OCT) who are prepared to take full clinical responsibility can take on referral refinement work (DM 19)
- Stepwise construction of referral refinement might mean ophthalmologists initially do all the image review, then handing this over to appropriately trained non-medical HCPs for an audited service (DM 20)
- Where a neighbouring eye department is running a successful surveillance programme for low risk patients, they may be prepared to take on another area as well, rather than setting up a fresh scheme (DM 23)

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**Adequate IT is a prerequisite for running virtual services. Some have not been able to start due its absence (DM 9), whilst others have had to shut down due slow IT making it unworkable (DM 10).**

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## Cost Effectiveness of referral refinement

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*Insertion of an OCT which is then virtually reviewed permitting ~75% of patients to be diverted back into screening or into a surveillance clinic.*

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Any referral refinement puts an extra step in the pathway for those patients who ultimately go on to being seen in clinic. A traditional system seeing all maculopathy referrals in clinic must be compared to the insertion of an OCT which is then virtually reviewed permitting ~75% of patients to be diverted back into screening or into a surveillance clinic.



One consultant had modeled this for their department based on 350 referrals annually and found the traditional model to cost £126,700, whereas this was reduced to £66,404 for the same patients to undergo an OCT refinement process (*DM 11*). The costs to patients and carers are not considered in this, as for 25% it creates an extra clinic visit, but this is unlikely to negate the savings on offer.

## Expansion of referral refinement into virtual diabetic retinopathy clinics

Whilst review of acquired images may permit low risk maculopathy to be managed efficiently, the next most numerous group of patients who may be better managed outwith the HES is the cohort with pre-proliferative retinopathy, classified as R2, who are difficult to discharge but who may remain stable for many years.

Some localities had services that did not refer R2 patients to the HES clinics:

- One R2 service serving >50,000 diabetics kept these patients within the DRS (*DM 8*)
- One department reported 8 years' experience of holding all R2 (without referable maculopathy) in digital surveillance (*DM 6*)
- Another unit had identified that 40% of the HES DR clinic load was R2 reviews, so their DRS is deploying wide field imaging systems in three screening centres in order to run a virtual R2 surveillance service. This last service modification has not been in operation long enough to be evaluated, but were aware of another locality in which this modification was tried but was felt to be insufficiently sensitive to pick up proliferative disease so that it had been discontinued (*DM 33*)

## One-stop Diabetic Laser clinics

There are advantages of one-stop clinics for patients, those who employ and accompany them as well as for clinical services. This is particularly true for diabetics who often have frequent health related appointments and a high DNA rate, which in itself is a predictor of sight-threatening disease<sup>186,187</sup> and could probably be helped by minimising the inconvenience created by multiple appointments amongst other factors.<sup>127,188</sup>

Despite these advantages only 12% of consultants running diabetic eye services were able to routinely offer same day focal or grid laser (4/34). The patient is there in the hospital, dilated and ready to receive what is usually a brief treatment but time constraints or logistical difficulties with availability of lasers make this impossible for many to realise. More than half (22/34) of departments provide appointments for diabetic macular laser within a month.

Pan-retinal laser photocoagulation (PRP) being more time consuming was generally only applied same day when clinically urgent, but 71% (24/34) departments were able to deliver PRP within 2 weeks of listing for all patients, and a further 23% (8/34) treat the majority within this timeframe, leaving only 2 departments routinely unable to start treatment within 2 weeks. It was noted that patients referred from the Diabetic Eye Screening Programme who require laser are on a monitored target. However, those detected in clinic are not on this target, which makes them a softer target for managers needing to defer appointments (*DM 33*). Another example of unforeseen consequence of targets was described as patients who might breach their referral to treatment target for laser treatment for proliferative disease were removed from the target if fluorescein angiography (FFA) was booked, which may help avoid the hospital breaching the target, but not the patient or eyesight (*DM 28*).

# Common themes affecting AMD and DR Quality assurance of eye Healthcare Professionals (HCPs) in medical retinal services



Clinical decision making roles in medical retina services have been greatly helped by the advances in imaging technology, and about two thirds (19/28) of departments interviewed now have non-ophthalmologists making clinical decisions in their AMD pathways. The majority of those (12/19) were optometrists, but nurse practitioners, nurse consultants, orthoptists and ophthalmic healthcare science practitioners are also involved.

For diabetes, the population referred to clinics is often already refined, but half (15/30) of consultants interviewed about their diabetic services had trained HCP to take on some clinical decision making workload; these were mostly optometrists (8/15) but also included screeners (4/15) and nurses (3/15).

The opportunity that exists to define a national Quality Assurance process and training programme for HCPs was pointed out (DM 33) and the newly published Common Competency Framework is a step in that direction, but at present each department establishes its own rules. This is something that needs to be changed and support for appropriate standardised training programmes is required to both promote this expansion in the trained workforce and to ensure safety for patients.

**DR** – For diabetic retinopathy services, the existence of a robust well established quality assurance process for the DRS is of great advantage as many departments utilise staff already engaged in the DRS for their virtual reviews and referral refinement. Nonetheless, due diligence must be paid to the potential negative impact of false negatives and appropriate measures be seen to be taken to mitigate this risk.

- In a department where screening graders run an OCT clinic for all maculopathy referrals in which all images are viewed by the consultant the correlation of the graders and the consultant is so high, they intend to move to a 10% sample of images to review (DM 12)
- A programme with 8 years' experience of screeners running virtual diabetic review clinics in the HES had initial quality assurance processes with double assessment but after a few months this was discontinued due to good correlation (DM 6)

**AMD** – In nascent non-medical HCP delivered AMD services, the path to quality assurance is less well trodden, and this is still a barrier to some trusts establishing, for example, nurse injectors (see below).

Of 16 consultants interviewed who had non-medical HCPs making clinical decisions in AMD clinics, and who detailed their quality assurance mechanisms, 7/16 relied solely on the apprenticeship model (as is used for training junior ophthalmologists) as the HCPs work alongside them, 6/16 audited the decision making process by auditing a sample of cases, and three started by double reviewing every case seen until competency was achieved and sufficient to permit relaxation of this review process.

## Better value investigations

### Fluorescein angiography (FFA)

Fundus fluorescein angiography (FFA) in the assessment of AMD is another potential area where patients might be saved from having hospital visits and invasive procedures that may not alter their care. Whilst it is clear that not every patient with apparent nAMD has this pathology,<sup>189</sup> it is not clear what impact routine FFA has on treatment decisions compared to targeted use of this investigation, and whether the benefit to patients of this routine practice is outweighed by the negative effects on patient experience. It is generally accepted that the gold standard for confirmation of diagnosis of nAMD or CNV is FFA, and that other modalities may provide false positives.<sup>190,191</sup>

No-one described routine performance of indocyanine green (ICG) angiography, despite this imaging modality having been shown to be useful in diagnosing non-responders to treatment with intravitreal injections.<sup>189,192</sup> More than a quarter (8/28) of consultants interviewed felt that a case by case decision should be made on whether FFA or ICG were appropriate or necessary to the treatment decision making process.

From the interviews, the spread of practice is detailed below:

- Only 2/28 departments reported ophthalmologists performing FFA (injections / cannulating)
- Same day FFA was always possible for 13/29 (45%) but never possible for 6/29 (21%)
- 3/32 (9%) reported FFA taking > 2/52 for half or more of their patients
- 20/29 (69%) obtained FFA on every newly diagnosed nAMD case
- 8/28 (28%) departments perform FFA on half or less of new nAMD cases
- 3 of those perform FFA on <10% of new cases (as it is “not going to change management”)
- Most commented they do not permit imaging to delay treatment

A research opportunity exists therefore identify the value added by routine FFA as compared to PRN, which could inform the decision to allocate or disinvest resources into this area. OCT angiography may progress to ease the needs for FFA but this is not sufficiently established as yet to judge its place in routine services.

## Optical Coherence Tomography (OCT)

All interviewees were able to get good same day access to OCT scanning as and when needed. Patients were not brought back on separate visits for OCT. There is, however, variation in the extent to which OCT scans are requested.

- Macular OCT and VA was recorded on every visit for injection including through the initiation (loading) phase in 28% (7/25) departments
- The majority (64%, 16/25) performed OCT scans routinely on patients at diagnosis but then not again until after the initiation phase
- The remaining 8% (2/25) only performed OCT when it was ‘needed’; so if at follow up there was still active disease and OCT was not going to inform the decision to inject then it was not performed. Such practices need to be balanced against the sensitivity and specificity of OCT imaging, as a recent systematic review has shown that the current OCT technology may not be as sensitive as FFA in the diagnosis of CNV.<sup>193-195</sup> The same Health Technology Assessment concluded that monitoring patients with nAMD using OCT alone to detect active nAMD should not be recommended.(Mowatt et al, 2014; Castillo et al, 2015) This is especially important as intraretinal cysts are generally considered as surrogate for nAMD activity, but known to occur with retinal degeneration or atrophy in the absence of vascular leakage/CNV activity<sup>190,196</sup>

For departments that do not work under “Payment by Results” (PbR), reducing the number of scans and angiograms is more clearly desirable as it saves departmental resources. For those who receive remuneration for investigations, the drive to minimise their use is less clear, particularly with OCT where the tariff reflects the capital outlay and depreciation of the equipment rather than the individual cost of performing the test. However, with many eye departments having just one monopoly purchaser of their services, and with that single purchaser having a finite budget, there is some incentive to keep costs to a minimum for that purchaser and ensure that the best value possible is provided. It is important to remember, however, that the continuing administration of intravitreal injections of anti-VEGFs without adequate objective monitoring may result in inappropriate treatment (under-, and over-treatment, as the case may be), in order to achieve cost saving.

Over-provision of equipment should perhaps be tolerated, especially where departments have just one OCT scanner. The lead time on procuring a replacement or repair in the event of it breaking down, might constitute a substantial clinical risk; one department reported having just got a back-up OCT scanner in order to protect their service from this risk (AMD 8).

## Reporting clinical outcomes

Given the current high cost of MR services, it would be reasonable for those paying for these services to demand evidence that value is being delivered, at least in terms of clinical outcomes.

Of 24 AMD lead consultants asked about this, 11/24 (46%) were using an EPR to monitor outcomes prospectively, and a further 3/24 had created their own spreadsheet based methods of prospective data collection. Six consultants reported undertaking periodic retrospective audit from the case records and 4 (17%) confessed to not undertaking any outcome monitoring.

This may become more important as time goes on and real-world benchmarks are established and audit required by commissioners. Where the absence of EPR or administrative audit support is weak, it would seem prudent to generate capacity to monitor outcomes which can drive audit cycles, prior to such data provision becoming mandatory or being demanded.

## Discharge

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Capacity in an eye service is enhanced by appropriate, prompt discharge. Confidence in secure pathways of clinical care in the community and clear routes of re-access for patients are likely to increase discharge rates. For both AMD and DR services, risk stratification of patients who are no longer receiving active treatment may permit a gradation of discharge options to be utilised.

Discharge to community services has been advocated as a way of reducing pressure on the HES,<sup>130</sup> and where IT can be configured to permit virtual review of OCT or other images, a system of tele-ophthalmology has been shown to work well to safely keep patients under review with appropriately trained community optometrists.<sup>197,198</sup>

### DNA rates

One consultant reported having had a rate of non-attendance for its diabetic clinics of 40% which wasted a lot of capacity. This is an established problem with diabetic services,<sup>187</sup> they instigated changes to counter this, focussing on patient education in clinic as suggested by the evidence base,<sup>199</sup> leverage of media opportunities with TV and newspaper to promote uptake and the deployment of a failsafe team who pick up on patients failing to attend and contact them to arrange a convenient re-appointment and encourage subsequent attendance. This combination of interventions, saw the non-attendance drop to less than 10%, and greatly reduce the inefficiency (*DM12*).

Departments need to know their DNA rates and many would advocate the utilisation of failsafe officers to prevent negative clinical consequences of failure to attend as a proportion of DNAs will be attributable to administrative errors and intensive risk management can therefore be protective. There is an extensive body of peer reviewed literature that could be explored around minimisation of DNA rates, such as by use of SMS text messages or informing patients of the cost of each appointment.<sup>200,201</sup>

### Eye Clinic Liaison Officers (ECLO) / Vision Support Workers

ECLO or vision support workers provide a valuable service in the clinic supporting patients with low vision and signposting them to appropriate services.

Twenty out of 27 (74%) departments with whom vision support worker / ECLO services were discussed had one in post. The funding sources varied:

- Charity funded
- Hospital funded
- Charity/Hospital joint
- CVI fee funded

One model of introducing a vision support worker /ECLOs to obtain pump-priming start-up salary funded through charitable support, which may be provided for the short term.. The value of the post can then be evaluated and demonstrated to the hospital/Trust, who may then be more willing to take on part or full funding thereafter. One consultant commented that “we keep the AMD service profitable so the trust can afford to fund the ECLo” (AMD 24). Departmental agreement to divert the fees received from certifying patients as visually impaired is another means that departments have used to fund an ECLo post.

## Considerations

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It must be emphasised that one size will not fit all in configuration of Medical Retina services; heterogeneity in patient characteristics<sup>206</sup> and local contexts make it impossible to be prescriptive, but common points for consideration are set out below.

### **Encourage managerial engagement with the projected growth**

- Emphasise to managers the importance of a departmental plan to cope with a 60% increase in DR and AMD case load over the next 20 years. Decide on specific interventions, and agree what level of demand would trigger the next step in the plan being implemented. Consider using the RCOphth “3 Step Plan” for reducing risks from outpatient delays

### **Refinement of referrals from the DRS**

- If all referable maculopathy is being reviewed face to face in HES, consider reviewing the images and categorising as A] High risk - must be seen in HES, B] low risk - can be seen again in the DRS in 6 months, and C] equivocal – could have an OCT and then decision made as to appropriate review. If this produces a useful reduction in patient numbers, consider training for a non-medical HCP, or move the task into the DRS itself

### **Virtual clinics for DR or AMD**

- Consider using this to follow up stable R2 if sufficient retinal coverage can be achieved at adequate quality by the available imaging modalities
- Consider what patient groups are lowest risk and could therefore be moved into a virtual clinic service (e.g. those who have been stable off treatment for 3 months or more)
- Consider training HCP’s who could review the images for this virtual service rather than the consultant undertaking this activity
- Investigate options for decentralised image acquisition for AMD virtual clinics if community OCT and cameras are in existence already

### **Injection services**

- Consider non-ophthalmologist injectors - identify staff who would be suitable for this role, and pursue training on specific courses / get experience at nearby units with non-medical HCP injectors
- Arrange to visit a unit running with higher throughput to see how this is managed if your service delivers less than 16 injections in a four hour dedicated injection session (where the injector is not also performing clinical assessment)
- Investigate the geography of the unit to optimise patient flow with a lower banded support staff maintaining patient this

### **Investigations**

- If your department is struggling with capacity for angiograms, consider a targeted approach such that investigations are only instigated when there is an expectation of this altering the management
- Where there is pressure on OCT provision, it could be decided not to get an OCT on patients who are receiving a planned block of injections until the next management decision is required. However, bear in mind that when it comes to determining response/non-response later, you may have incomplete data to allow a swift decision

## **Administration and Monitoring**

- It is unlikely that monitoring of clinical outcomes will remain optional in the long term. Plans should be put in place to permit outcome audit where this is not currently done
- Monitor DNA rates. Each DNA creates a loss of capacity (and income under PbR in England) that makes the economic case for a failsafe officer, nurse educator or other interventions to work at minimising DNA
- Review appointment timing is critical; follow up times should be monitored, causes for any delays identified and safety mechanisms implemented

## **Vision Support / ECLO Services**

- Negotiate with charities to fund an ECLO/ vision support worker in the short term, but bargain with the Trust to take up this funding if the post is seen to provide good value after the initial charitable support dries up. Departmental agreement to divert the fees received from certifying patients as visually impaired is another means that departments have used to fund an ECLO post

# Appendix A

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## The Way Forward – Methodology

### Introduction

The Way Forward project is an exciting opportunity to identify and disseminate current best practice models in the delivery of eye care in the UK. The substantial breadth of the work, including prevalence, projected trends in prevalence and absolute cases numbers over the next 20 years across the major ophthalmic diseases of public health significance (cataract, glaucoma, Diabetic retinopathy and AMD as well as emergency eye care service provision) in all countries within the UK, necessitates a high level overview approach, but with specific detailed examples to illustrate themes, and provide impetus for positive change. Literature review will be combined with some primary data collection in the form of surveys of current practice to determine what innovations and service designs have been successfully employed already.

The Way Forward project is a shared learning opportunity, and to that end, a survey of UK departments was undertaken by phone interview employing a semi-structured interview template to guide interviews.

### Literature Search

Literature search included both peer reviewed publications via search of Medline and a search of the grey literature. Exhaustive literature review such as that which would be undertaken for a systematic review, was not be achievable or appropriate within the terms of reference of this work, so a search strategy for each major condition was undertaken selecting for papers where the condition is a major MeSH term and appropriate sub-headings will be included rather than exploding all trees.

Age-related Macular Degeneration - (“Macular Degeneration/economics”[Mesh] OR “Macular Degeneration/epidemiology”[Mesh] OR “Macular Degeneration/organization and administration”[Mesh] OR “Macular Degeneration/prevention and control”[Mesh] OR “Macular Degeneration/statistics and numerical data”[Mesh] ) AND ( “UK” OR “Northern Ireland” OR “Scotland” OR “England” OR “Wales”)

Using PubMed (www.pubmed.org accessed 18/11/2015), 229 citations were returned of which 69 were deemed relevant and full text retrieved.

Diabetic Retinopathy - (“Diabetic Retinopathy/diagnosis”[Majr] OR “Diabetic Retinopathy/economics”[Majr] OR “Diabetic Retinopathy/epidemiology”[Majr] OR “Diabetic Retinopathy/organization and administration”[Majr] OR “Diabetic Retinopathy/prevention and control”[Majr] OR “Diabetic Retinopathy/statistics and numerical data”[Majr] )AND ( “UK” OR “Northern Ireland” OR “Scotland” OR “England” OR “Wales”).

Using PubMed (www.pubmed.org accessed 18/11/2015), 413 citations were returned of which 130 were deemed relevant and full text retrieved.

To look outside of the peer reviewed literature available through PubMed, other relevant databases were searched.

The Cumulative Index of Nursing and Allied Health Literature (CINAHL), Health Management Information Consortium (HMIC) and Health Business Elite data bases were also searched with the strategy (“UK” OR “Northern Ireland” OR “Scotland” OR “England” OR “Wales”) AND (ophth\* OR eye) AND (service OR clinic OR design) which produced 83, 119 and 55 references respectively of which 47 references were taken up for review. Particular key references in each subject area were entered into the Science Citation Index.

This search strategy was designed to have a higher specificity than sensitivity for relevant papers for efficiency. To mitigate the risk of missing important papers, for the older key papers identified from the search, future studies that cited those papers were then also viewed and for more recent papers, their references also inspected.

## **Prevalence Estimates and Case numbers for the UK up to 2035**

With age as the most significant risk factor for the major conditions of interest, prevalence projections based on demographic trends will be produced nationally using case definitions and age stratified data from relevant populations. Other risk factors such as ethnicity, obesity and smoking are not static in the UK population, and although predictions regarding changes in these risk factors, stratified by age, across the country, applied to prevalence data derived from relevant populations might have been possible, more benefit was seen to lie in discussion of trends in these risk factors.

The interest we have in prevalence (for chronic problems such as glaucoma and diabetic retinopathy) or incidence (for treatable conditions such as symptomatic cataract), is primarily for predicting the demand on ophthalmic services. The report acknowledges that the link between national disease prevalence and the demand for services is not strong. This is exemplified by the regional variation seen in the UK in the numbers of cataract operations performed per 100,000 per annum. This figure is reported to vary from <300 cataracts per 100,000 per year to >800 cataracts per 100,000 per year (as noted in the RCOphth Cataract Commissioning Guidance).<sup>148</sup> It is unlikely that this difference is accounted for by local variations in prevalence alone. However, such prevalence/incidence figures are necessary.

The prevalence estimates and methodology employed, using the NEHEM, are expanded upon in Appendix B.

## **Interviews with UK consultants leading cataract services to identify good practice examples**

In the rapidly changing landscape of health service delivery in the UK, it must be recognised that not all good practice examples will have reached publication.

Using the RCOphth database of lead clinicians, emails were sent to every lead clinician in the UK asking them to nominate colleagues who might be prepared to be interviewed about the service configuration in their departments for Cataract, Glaucoma, AMD, DR and Emergency Eye Care. In some cases, one consultant was nominated to be interviewed for more than one sub-specialist area. More than 200 structured interviews took place with lead clinicians.

Nominated consultants were then contacted by email to arrange an interview time using a scheduling application, and the interview was then conducted using a semi-structured interview template, with data recording done into a spreadsheet for later thematic evaluation. Examples of poor practice or instances where departments are experiencing difficulty in realising the quality and quantity of service that they would have liked to deliver were seen as being as informative as the examples of good practice.

## **Project Output**

It was initially intended that one single written report would be released detailing the findings of The Way Forward. However, with the volume of data gathered from interview and literature search, it was felt that it might be difficult to keep the document acceptably concise without limiting the opportunity to present different models of practice. It was therefore concluded that separate reports should be prepared for different sub-speciality areas. These reports were prepared by the principal investigator, reviewed by members of the Leeds Ophthalmic Public Health Team and The Way Forward Project Steering Group along with reference consultants. After revision, a pre-final draft is then to be circulated to all consultants who had participated in The Way Forward project interviews for final input prior to RCOphth ratification and dissemination.

Dissemination through national congresses and regional educational meetings is intended. The success of the project can be seen to pivot around whether any change in local practice is facilitated by the output, either by reports or by presentations.

# Appendix B

## Age-related Macular Degeneration: the growing demand – Projections for the UK 2015-2035

In order to facilitate service capacity and workforce planning for Medical Retina services, it is necessary to attempt to quantify the expected growth in demand due to Age-related Macular Degeneration (AMD). For AMD, the major risk factor being age, we need to understand the expected future demographic changes, and apply prevalence data from existing population based survey data to those. Risk factors other than age exist such as diet and smoking, but predicting how these will change and working these effects into a model may not increase the accuracy or utility of the modelling exercise. Socio-economic status (SES) has not been shown to be linked to visual acuity at presentation,<sup>207</sup> and as life-expectancy correlates positively with SES, but other risk factors are negatively associated, it is hard to predict what impact SES will have on the burden of disease. For diabetes, although age is a risk factor, obesity, genetics and other lifestyle factors are also at play whose future influence is harder to model and this is discussed in the main report and existing projections presented.

### Growth projections for the elderly population of the UK

The population growth projections for each of the 4 nations of the UK derived from the ONS are given in table B1. However, for AMD service planning, it is not the total population growth that is of concern, but the projected increasing age of that population, with a diminishing ratio of those of working age compared to those of retirement age (ratio in 2010 of 3.16, dropping to 2.87 by mid-2035).<sup>7</sup>

|                | 2010 | 2015 | 2020 | 2025 | 2030 | 2035 |
|----------------|------|------|------|------|------|------|
| United Kingdom | 62.3 | 64.8 | 67.2 | 69.4 | 71.4 | 73.2 |
| England        | 52.2 | 54.5 | 56.6 | 58.6 | 60.4 | 62.1 |
| Wales          | 3.0  | 3.1  | 3.2  | 3.2  | 3.3  | 3.4  |
| Scotland       | 5.2  | 5.4  | 5.5  | 5.6  | 5.7  | 5.8  |
| N. Ireland     | 1.8  | 1.9  | 1.9  | 2.0  | 2.0  | 2.0  |

Table B1: ONS 2010 data based projections for UK population growth (millions)

In 2010 there were estimated to be 4.9 million UK residents over 75 years of age (1.4 million >85 years) whereas by 2035 the total over 75 years is expected to be 8.9 million (3.5 million >85 years). Figure B2 below graphically demonstrates this population shift.

The demographic shift can also be seen in the life-expectancy figures which rose between 1990 and 2013 by 5.4 years (95%CI 5.0-5.8) from 75.9 to 81.3 years.<sup>208,209</sup>

In 2014, in England and Wales as a whole, there were 870 people aged 90 and over per 100,000 population, compared to 739 people aged 90 and over per 100,000 population in Scotland and 654 in Northern Ireland. These differences to some extent reflect the life expectancy at older ages in that, at age 85, the average English or Welsh man can expect to live another 5.9 years, or 6.8 years for females, compared with the average Northern Irish 85 year old living 5.7 years (male) and 6.6 years (female) and in Scotland the expectancy is 5.5 years (male) and 6.4 years (female).<sup>209</sup>

### Epidemiological modelling of growth in the numbers of patients with AMD

If we can estimate the number of people in each age group at various time points into the future, and we can estimate the age stratified prevalence of AMD in a representative population, then we can produce estimates of the total numbers of people with AMD at those future time points.

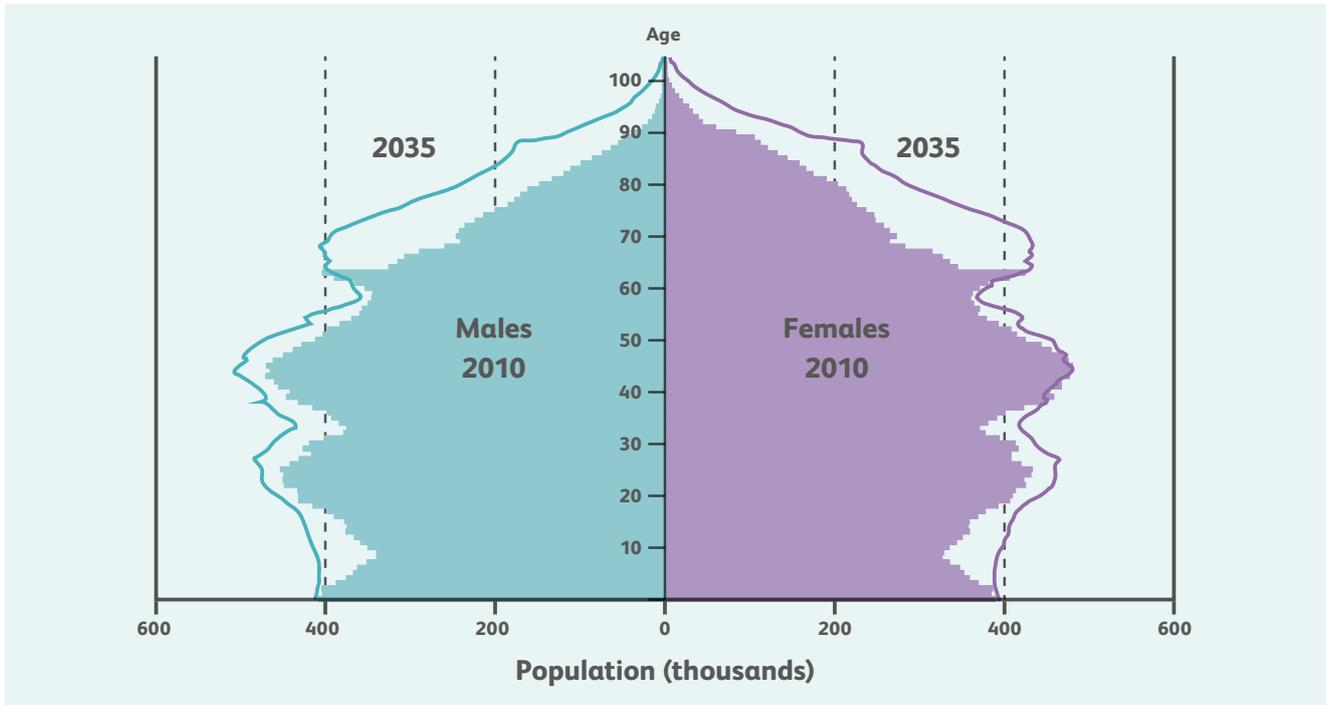


Figure B2. Estimated and projected age structure of the UK population mid-2010 and mid-2035

The National Eye Health Epidemiological Model (NEHEM), is an online resource ([www.eyehhealthmodel.org](http://www.eyehhealthmodel.org)) that permits national or local estimation of the numbers of patients with various ophthalmic diagnoses. NEHEM was created by the Public Health Action Support Team, having been commissioned by a consortium of interested bodies including the Royal College of Ophthalmologists, the Association of British Dispensing Opticians, the Association of Optometrists, the College of Optometrists, the Federation of Ophthalmic and Dispensing Opticians; the consortium acknowledged the Central (LOC) Fund for their support in commissioning this, and the LOC Support Unit (LOCSU) for hosting the model as an online resource.

In order to populate the NEHEM model, projections of the UK population broken down by age, ethnicity and gender up to 2035 are needed. The ONS published census data gives the breakdown of the UK population by gender stratified by age from the 2011 national census (figure B3).<sup>210</sup>

ONS also release projections of the UK population 2010–2035 stratified by age (figure B4), to which the proportionate gender distribution from the 2011 census can be applied.

| Age     | Persons   | % Males | Males     | % Females | Females   |
|---------|-----------|---------|-----------|-----------|-----------|
| 50 – 54 | 4,095,000 | 49.5    | 2,029,000 | 50.5      | 2,066,000 |
| 55 – 59 | 3,614,000 | 49.4    | 1,785,000 | 50.6      | 1,829,000 |
| 60 – 64 | 3,807,000 | 49.1    | 1,869,000 | 50.9      | 1,939,000 |
| 65 – 69 | 3,017,000 | 48.5    | 1,464,000 | 51.5      | 1,555,000 |
| 70 – 74 | 2,463,000 | 47.2    | 1,163,000 | 52.8      | 1,300,000 |
| 75 – 79 | 2,006,000 | 45.1    | 904,000   | 54.9      | 1,102,000 |
| 80+     | 2,890,000 | 36.9    | 1,066,000 | 63.1      | 1,826,000 |

Figure B3: Census data from UK 2011, ONS210

|       | 2010 | 2015 | 2020 | 2025 | 2030 | 2035 |
|-------|------|------|------|------|------|------|
| 50-59 | 8.08 | 8.68 | 8.77 | 8.34 | 8.23 | 8.66 |
| 60-69 | 6.11 | 6.47 | 6.89 | 7.28 | 7.87 | 7.99 |
| 70-79 | 4.80 | 5.12 | 5.54 | 6.14 | 6.58 | 6.71 |
| 80+   | 3.16 | 3.50 | 4.00 | 4.78 | 5.41 | 6.20 |

Figure B4: Projections of the UK population 2010 – 2035 stratified by age (millions)

|       | 2010 | 2010 | 2015 | 2015 | 2020 | 2020 | 2025 | 2025 | 2030 | 2030 | 2035 | 2035 |
|-------|------|------|------|------|------|------|------|------|------|------|------|------|
|       |      |      | ♂    | ♀    | ♂    | ♀    | ♂    | ♀    | ♂    | ♀    | ♂    | ♀    |
| 50-54 | 2.13 | 2.17 | 2.28 | 2.33 | 2.32 | 2.34 | 2.20 | 2.23 | 2.17 | 2.20 | 2.28 | 2.31 |
| 55-59 | 1.88 | 1.91 | 2.02 | 2.05 | 2.03 | 2.08 | 1.93 | 1.98 | 1.90 | 1.95 | 2.00 | 2.05 |
| 60-64 | 1.67 | 1.73 | 1.77 | 1.84 | 1.89 | 1.96 | 1.99 | 2.07 | 2.16 | 2.24 | 2.19 | 2.27 |
| 65-69 | 1.31 | 1.39 | 1.39 | 1.47 | 1.48 | 1.57 | 1.56 | 1.66 | 1.69 | 1.79 | 1.71 | 1.82 |
| 70-74 | 1.25 | 1.40 | 1.33 | 1.49 | 1.44 | 1.61 | 1.60 | 1.79 | 1.71 | 1.91 | 1.75 | 1.95 |
| 75-79 | 0.97 | 1.18 | 1.04 | 1.26 | 1.12 | 1.37 | 1.24 | 1.51 | 1.33 | 1.62 | 1.36 | 1.65 |
| 80+   | 1.16 | 1.99 | 1.29 | 2.21 | 1.47 | 2.52 | 1.76 | 3.02 | 1.99 | 3.41 | 2.29 | 3.91 |

Figure B5: Projections for UK population 2010-2035 by gender (millions)

Because the ONS published projections up to 2035 are stratified in 10 year age bands (i.e. 50-59, 60-69 etc), and the NEHEM uses different prevalence for each 5 year age band (i.e. 50-54, 55-59), the proportionate distribution of population between the first and second half of each decade found at the 2011 census was applied to the projection data to produce figures stratified in 5 year age bands. To these figures, the gender distribution for each 5 year age band from 2011 census data was applied to produce figure B5.

|          | 2006   | 2031   | 2056   |
|----------|--------|--------|--------|
| White    | 54,591 | 55,646 | 51,715 |
| Mixed    | 859    | 2,234  | 4,207  |
| Asian    | 3,122  | 8,309  | 14,010 |
| Black    | 1,411  | 2,998  | 4,789  |
| Other    | 403    | 1,748  | 3,326  |
| Total UK | 60,587 | 70,936 | 78,047 |

Table B6: Estimates and Projections of UK Ethnic distribution mid-2006 to mid-2056 (thousands) 18

As there has been notable variation in nAMD prevalence between different ethnic groups,<sup>8,12</sup> the NEHEM requires population breakdown by ethnicity at various time points into the future. Although there are some detailed short term projections of the growth of ethnic minorities within the UK population which have been prepared at local level in cities or regions of the UK, none has been published at the national level since 1979 when the Office of Population Censuses and Surveys (OPCS, now ONS) provided the first UK projections of 'ethnic minority' populations (Immigrant Statistics Unit 1979).<sup>18</sup> With no official statistics or projections to inform our estimates, the academic literature was searched, and although no study

regarding ethnicity distribution within the UK population stratified by age was identified, one study gave UK ethnographic projections for 2031 and 2056, taking 2006 data as a baseline (table B6).

There was no finer granularity in the projection data, so by interpolation, percentages were produced for the interim and applied at each time point under consideration for this project (table B7).

|       | 2006   | 2006 | 2010  | 2015 | 2020  | 2025 | 2030 | 2031   | 2031 | 2035   |
|-------|--------|------|-------|------|-------|------|------|--------|------|--------|
|       | pop.   | (%)  | (%)   | (%)  | (%)   | (%)  | (%)  | pop.   | (%)  | (%)    |
| White | 54,591 | 90.1 | 88.26 | 85.9 | 83.58 | 81.2 | 78.9 | 55,646 | 78.4 | 76.6   |
| Asian | 3,122  | 5.2  | 6.2   | 7.5  | 8.8   | 10.1 | 11.4 | 8,309  | 11.7 | 12.7   |
| Black | 1,411  | 2.3  | 2.6   | 3    | 3.4   | 3.7  | 4.1  | 2,998  | 4.2  | 4.5    |
| Mixed | 859    | 1.5  | 1.8   | 2.1  | 2.4   | 2.7  | 3    | 2,234  | 3.1  | 3.3    |
| Other | 403    | 0.7  | 1     | 1.3  | 1.7   | 2.1  | 2.4  | 1,748  | 2.5  | 2.8    |
| Total | 60,587 |      |       |      |       |      |      | 70,936 |      | 78,047 |

Table B7: UK Population Ethnicity Projections

The main ethnic variation in AMD distribution is the lower prevalence of blinding AMD seen in the black population.<sup>12</sup> The NEHEM therefore just requires data divided between black and others. The proportional adjustments to the prevalence based on ethnicity for NEHEM were made using data from the American Eye Diseases Prevalence Research Group.<sup>10</sup>

Data was thus created to populate the NEHEM model, and projections made for prevalence in the population >50 and the absolute numbers of cases expected in the UK of nAMD, geographic atrophy and

dry AMD manifest only with drusen (table B8). This is not, of course the number of patients that will present to our departments, or the number of cases who are symptomatic. The case definitions from the reference studies used to create NEHEM must be understood to see what is being predicted.

|      | NAMD Cases       | Geographic Atrophy | Drusen Cases        |
|------|------------------|--------------------|---------------------|
| 2010 | 402,559<br>1.82% | 195,768<br>0.88%   | 2,520,079<br>11.38% |
| 2015 | 439,854<br>1.85% | 213,532<br>0.90%   | 2,720,545<br>11.44% |
| 2020 | 490,189<br>1.95% | 237,913<br>0.94%   | 2,955,305<br>11.73% |
| 2025 | 567,381<br>2.14% | 275,705<br>1.04%   | 3,270,846<br>12.32% |
| 2030 | 629,283<br>2.24% | 305,567<br>1.09%   | 3,547,643<br>12.63% |
| 2035 | 697,947<br>2.36% | 337,912<br>1.14%   | 3,803,293<br>12.87% |

Figure B8: Way Forward projections for UK case numbers 2010-2035

For prevalence estimates, candidate studies were considered. Of all the UK studies, the North London Eye Study<sup>211</sup> and the meta-analysis by Owen et al<sup>31</sup> were considered most suitable for inclusion, particularly given their focus on the UK population. However both only assessed the prevalence of visually impairing age related macular disease, restricted their assessment to those aged 75 or older and did not specifically look for drusen.

The EUREYE study was selected therefore as it was a large (>5,000 participants) multicentre, population-based cross-sectional study with retrospective and current exposure measurements. It included seven study centres from Norway, Estonia, Northern Ireland, United Kingdom, France, Italy, Greece and Spain, so was felt to offer prevalence estimates from an appropriately representative population.<sup>212,213</sup>

The NEHEM utilises International Age Related Maculopathy (ARM) Epidemiological Study definitions,<sup>214</sup> such that:

- **Geographic Atrophy** – Any sharply delineated roughly round or oval area of hyperpigmentation or depigmentation or apparent absence of the RPE in which choroidal vessels are more visible than in surrounding areas that must be at least 1.75 mm in diameter.
- **Drusen** – refer to patients with drusen but no geographic atrophy or manifestation of neovascularisation
- **NAMD** – one or more of the following:
  - RPE detachments
  - sub-retinal or sub-RPE neovascular membranes
  - epiretinal/ intraretinal/ sub retinal/ or sub pigment epithelial scar/glia tissue or fibrin-like deposits
  - sub-retinal haemorrhages that may be nearly black, bright red, or whitish-yellow and that are not related to other retinal vascular disease
  - hard exudates (lipids) within the macular area related to any of the above, and not related to any other retinal vascular disease

This is clearly and confessedly a broad, inclusive definition of wet ARMD and is independent of the degree of visual impairment, so in as much as case definition defines the accuracy of prevalence estimation, the NEHEM can be said to utilise a maximum estimate.

## AMD Projection Summary

As we are interested primarily in demand, and it is unclear what the conversion factor is between prevalent AMD and demand on services, the key messages from The Way Forward projections up to the year 2035 are in the percentage increase in the number of people with disease (see Appendix B for case definitions and full tables):

- Neo-vascular AMD (nAMD) cases will rise by 59% from 2015 to 2035 (29% rise from 2015-2025) with the prevalence in the population over 50 rising from 1.85% in 2015 to 2.36% in 2035 as the number of elderly rises
- Geographic atrophy (GA) cases will increase by 58% from 2015 to 2035 (29% from 2015-2025)
- A 40% rise in the number of people with drusen is predicted from 2015 to 2035 such that the total number would be 3.8 million people, representing 12.9% of those over the age of 50

If the number of people with GA or nAMD rises by nearly 30% in the next 10 years, up to 60% growth in the next 20 years, this is clearly going to stretch both ophthalmic services and the support structures that exist to help those with visual loss. Inaction therefore is not an option. Changes to the way we deliver AMD services are inevitable as we are not expecting a 60% rise in the number of consultant ophthalmologists in the next 20 years.

## Appendix C

Clinical leaders need to understand the interaction between demand and capacity in order to be able to provide for a future in which demand grows by approximately 22% every ten years up to 2035. The outline of a capacity / demand model below should permit the mapping of current service and empower for future planning on the basis of expected increases.

Relevant questions include:

- Where is our department sitting on the demand/capacity graph for the various sub-specialty services we provide?
- Are there obvious inefficiencies that are reducing our effective capacity?
- What was the last thing we did to increase our capacity? (e.g. new staff member or waiting list initiatives)
- What steps will we take in the short term to ensure that being under capacity does not lead to delays that put patients at risk?
- What is our next step to increase permanent capacity? What will be the trigger point that makes us act to increase capacity?

## The Capacity and Demand Model

In business, capacity dropping below demand means losing customers, so increments in capacity are generated when the crisis point (★) of demand equalling capacity is reached figure C1. In publicly funded healthcare, the managerial drives are more strongly orientated towards avoidance of creating unused capacity (figure C2). The trigger point (★) for creation of more capacity is less well defined, but is likely to be driven by the growth of the backlog, represented by the shaded area under the demand curve. The incremented capacity will, in order to avoid excess capacity, aim to create a capacity/demand equilibrium hence building to match the current demand, but without allowance for expected future demand growth. One consultant interviewed for The Way Forward project described this dynamic; “we don’t plan for growth, but just for what is currently required. We know a wave of patients is going to hit us, but nothing is done until there is a large backlog, adverse outcomes, patient complaints - and only then, is there enough of a driver for the managers to expand capacity - but as the service grows - the cycle repeats itself. Proactive planning is needed rather than just responding to serious untoward incidents (SUI).”(AMD27)

*Proactive planning is needed rather than just responding to serious untoward incidents (SUI).”(AMD27)*

Whilst this behaviour in health management would be contrary to good business, it is rooted in the need to minimise costs. The ideal of balancing capacity and demand intrinsically requires excess capacity, as there will be fluctuation in both demand (patient flow) and capacity (staff sickness / leave). Every time there is an excess of demand, the surgical waiting list or clinic backlog is added to. When there is an excess of capacity (e.g. patients failing to attend appointments), it is harder to benefit from this unplanned excess capacity. Hence, even where capacity matches demand in theory, some capacity is wasted due to short term variation, and waiting list initiatives and backlog clinics are often needed to maintain the status quo.<sup>215</sup>

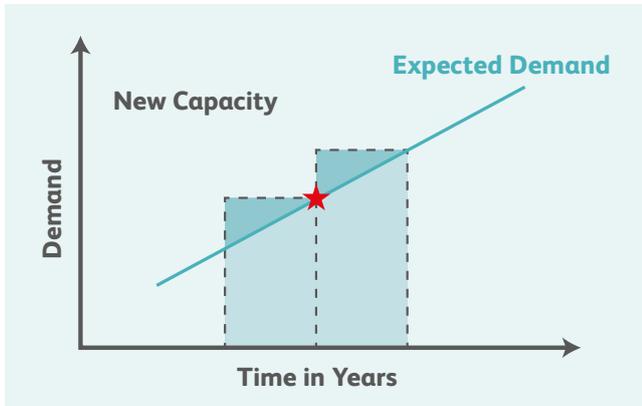


Figure C1: Capacity is incremented in advance of the expected growth in demand

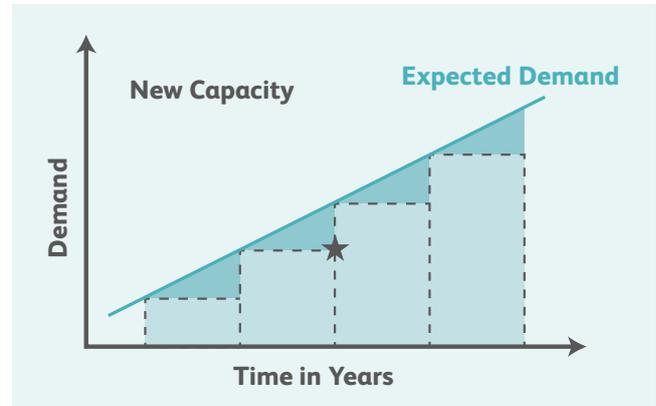


Figure C2: Capacity increments lag behind expected growth in demand

So in figure C3, the mean capacity might equal the mean demand, but a backlog will still develop. NHS management experience tells us that it is the capacity side that brings more variation to the equation, as staffing and equipment issues cause large unexpected drops in capacity that are not easily remedied in the immediate timeframe needed to avoid loss of activity.<sup>215</sup>

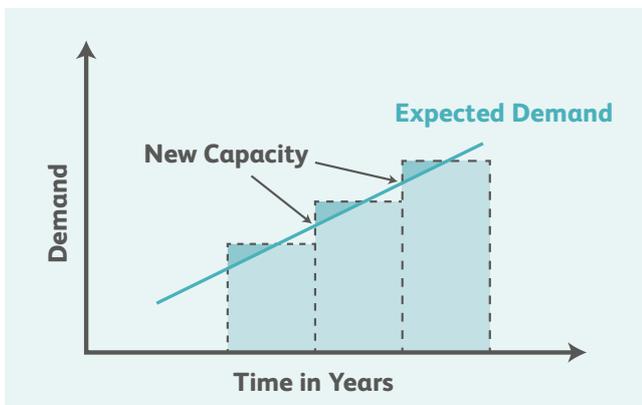


Figure C3: Mean capacity and demand equilibration

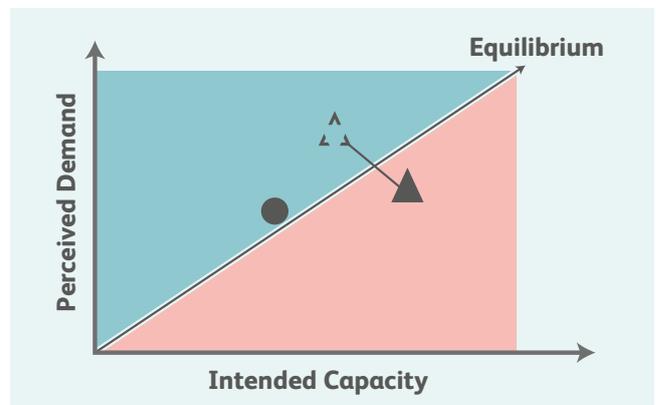


Figure C4: Individual services can be mapped to their current

## Demand management and potential capacity maximisation

As we consider our own situations, which may well be different for each sub-speciality service offered, we can place ourselves on a graph of perceived demand plotted against the capacity we intend to provide.

Hence a unit may have a cataract service (●) that is almost coping but requires occasional weekend “initiative” lists in order to avoid breaching the Referral to Treatment Time (RTT) target. The newly built injection facilities and recently trained nurse injectors may, by contrast have moved the previously failing macular service (▲) into a healthy position to cope with current demand and the expected future rise (figure C4).

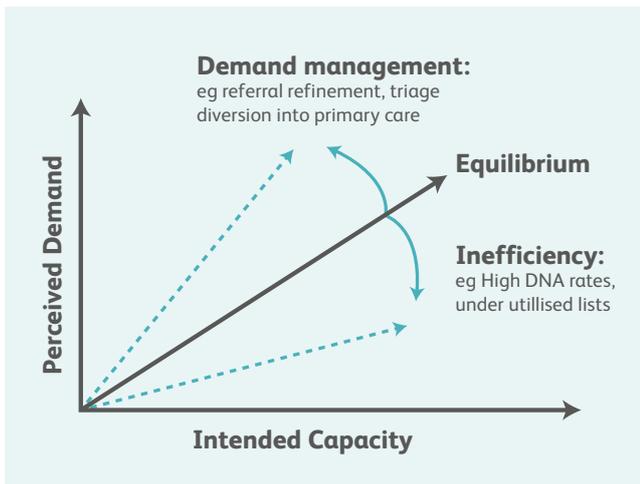


Figure C5: The equilibrium can be shifted to optimise current capacity

When placing our services on this graph, it is important to recognise that the equilibrium line is not fixed, and that factors from either side can shift this (figure C5). Before employing more staff and building more rooms, good management will want to examine potential for reducing inefficiencies and managing the demand side such that the same intended capacity meets a greater amount of perceived demand.<sup>216</sup> If a department has been traditionally performing six cataract operations under local anaesthetic (LA) per four hour operating list, but by improving turnaround time between cases increases this to 8 cases per four hour list, this increase in capacity of 33% permits the department to stay on top of the predicted growth in demand for cataract surgery for at least the next 10 years.

## You will always be under-capacity: how are you going to deal with it?

In any well managed eye department, if there were more capacity than demand, staff would be re-assigned to other tasks to prevent wastage. This appropriate intolerance for being over-capacity, and inevitable short term variation (sickness, DNA, equipment failure) that waste intended capacity, combine to the inevitable trend toward every eye department feeling stretched. If we accept this assessment, it is reasonable for departments to decide how they are going to deal with that (e.g. waiting lists initiatives, locums) and to cost that into their services. This proactive approach to being under-capacity should contribute to the protection of patients. The point at which it is decided to put on new permanent capacity (★ figure C2) would be determined by the time when the cost of permanent new capacity (e.g. new ophthalmologist or HCP team member) becomes less than the cost of the temporary capacity expansion plan, which would be typically more expensive per patient episode.

## Appendix D

### A Sustainable future for ophthalmology: The Triple Bottom Line

The Way Forward explores the mechanisms whereby ophthalmologists are meeting the increased demand on services and considers how to deliver increased service capacity in a high quality, **sustainable** way.

When developing eye services the impact of developments on people, profit and planet must be considered.<sup>202</sup> In order to be sustainable, developments must meet the **Triple Bottom Line** of minimising **economic** and **environmental impact** (e.g. waste and carbon footprint)<sup>203</sup> whilst optimising **social value** (e.g. quality and patient experience).<sup>204</sup> In general this goal can be achieved by employing the principles of sustainable clinical practice: disease prevention and health promotion, patient education and empowerment, lean service delivery and preferential use of treatment options with lower environmental impact.<sup>205</sup>

This report highlights a range of different approaches which can be taken to increase the overall sustainability of eye services given the restrictions on ophthalmologist numbers expansion and well established wider eye healthcare team supported models. Service delivery options that promote capacity include:

- **Broadening the base of the Consultant supported pyramid:** increase capacity at lower cost through senior ophthalmologist supported training, accreditation and ongoing clinical governance of increasing numbers of MDT clinicians

- **“One-stop” pathways** where all measures are taken to minimize the number of steps in the pathway
- **Minimise low value activities** by ensuring everything has been done to reduce false positive referrals and arrive at definitive management and discharge or risk-stratified follow-up
- **Reduce travel costs and carbon footprint** of multiple patient and staff journeys by rationalizing the number and location of sites, case and skill mix by local determination of the best ‘economy of scale’ considering the relative merit of larger high volume centralized units versus multiple smaller units
- **IT supported decentralisation and virtual review** – optimise a hybrid of HES in-house services integrated as appropriate to the local context with community ophthalmology services, community optometry or GPSI services to reduce the costs, inconvenience and environmental impact from traditional face to face, multiple journey, multiple location care
- **Efficient use of Estate and Equipment** – Reduce underutilization of expensive estate and equipment which is historically very common at most locations and most service delivery models. Going paper-light/paperless with Electronic Patient Records particularly with clinical information exchange between primary and secondary healthcare and joined up with ECLO and social rehabilitation care

NHS Commissioning guidance and further information on sustainability and population planning are available at [www.rightcare.nhs.uk](http://www.rightcare.nhs.uk) and [www.sustainablehealthcare.org.uk/resources/publications](http://www.sustainablehealthcare.org.uk/resources/publications) (Sustainable System-Wide Commissioning Guide).

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