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Healthcare Inspectorate Wales

Ophthalmology Services

Thematic Report
2015-16

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In writing:

Communications Manager
Healthcare Inspectorate Wales
Welsh Government
Rhydycar Business Park
Merthyr Tydfil
CF48 1UZ

Or via

Phone: 0300 062 8163
Email: hiw@wales.gsi.gov.uk
Fax: 0300 062 8387
Website: www.hiw.org.uk

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Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator of healthcare in Wales

Our purpose

To provide the public with independent and objective assurance of the quality, safety and effectiveness of healthcare services, making recommendations to healthcare organisations to promote improvements.

Our values

- **Patient-centred: we place patients, service users and public experience at the heart of what we do**
- **Openness and honesty: in the way we report and in all our dealings with stakeholders**
- **Collaboration: building effective partnerships internally and externally**
- **Professionalism: maintaining high standards of delivery and constantly seeking to improve**
- **Proportionality: ensuring efficiency, effectiveness and proportionality in our approach.**

Our Outcomes

Through our work we aim to:

Provide assurance:	**Provide independent assurance on the quality, safety, and effectiveness of healthcare by reporting openly and clearly on our inspections and investigations.**
Promote improvement:	**Encourage and support improvements in care through reporting and sharing good practice and areas where action is required.**
Strengthen the voice of patients:	**Place patient experience at the heart of our inspection and investigation processes.**
Influence policy and standards:	**Use our experience of service delivery to influence policy, standards and practice.**

1. Foreword

In the 2015/16 Healthcare Inspectorate Wales (HIW) Operational Plan, HIW proposed to undertake a thematic review relating to ophthalmology. This was due to the concerns being highlighted across Wales relating to the waiting times being experienced by ophthalmology patients and the potential for harm that could occur as a result.

The review set out to look across the boundaries of primary and secondary care to examine how providers were delivering and developing services, and to define the care and support required by patients. Due to the risks associated with any delay in treatment for patients with 'wet' Age Related Macular Degeneration (AMD), it was decided that the review would be based around the 'wet' AMD pathway.

The aim of the review was to assess how effectively health boards have been utilising service integration as a means of making the best use of the breadth of expertise and resources available.

In 2014-15 Health Boards in Wales were given £16 million to fund AMD services. The National Ophthalmic Implementation Plan[1] was also launched by Welsh Government in January 2015. The purpose of the National Ophthalmic Implementation Plan is '***to improve patient experience and deliver sustainable services***'. The plan requires health boards to understand and measure demand and capacity for the main subspecialties in ophthalmology. The purpose of the national planned care programme is to provide "sustainable" planned care services, and to optimise the patient experience of using planned care services.

This thematic report brings together and examines our findings following the fieldwork undertaken. It aims to identify common issues being experienced across Wales as well as some of the initiatives being introduced in areas in attempt to improve services. Recommendations are included for health boards and Welsh Government.

[1] http://gov.wales/docs/dhss/publications/150130opthamicimplementen.pdf

‘Wet’ Age-related Macular Degeneration (AMD)

‘Wet’ Age-related Macular Degeneration (AMD) is the leading cause of irreversible blindness in Wales[2]. The condition presents with a sudden disturbance of central vision and may progress rapidly. It is characterised by the growth of abnormal, leaky blood vessels under the central part of the retina (known as the macula). The most aggressive forms cause irreversible damage within weeks. The early diagnosis, treatment and timely monitoring of ‘wet’ AMD is essential for reducing the risk of severe vision loss.

The condition occurs in people over the age of 50.

There is no cure for ’wet’ AMD. The aim of treatment is to stop leakage, reduce the risk of bleeding and preserve remaining vision. Treatment involves injecting medicine directly into the anaesthetised eye, whilst management also involves the rehabilitation of vision with low vision aids such as magnifiers or adaptations to the home to maintain independence.

[2] http://brief.euretina.org/research/amd-continues-to-be-the-leading-cause-of-vision-loss-in-england-and-wales

2. Executive summary

HIW completed a thematic review relating to ophthalmology, focusing on 'wet' AMD services. The review set out to look across the boundaries of primary and secondary care to examine how providers were delivering and developing the care and support required by patients. The aim of the review was to assess how effectively health boards have been utilising service integration as a means of making the best use of the breadth of expertise and resources available.

Our review consisted of two phases. Phase one involved interviews with senior representatives from all health boards. Phase two involved additional interviews with operational staff from three selected health board areas namely Betsi Cadwaladr University Health Board, Cardiff and Vale University Health Board and Hywel Dda University Health Board.

The main issue for eye care services across Wales is insufficient capacity in secondary care to meet current demands. This issue is not restricted to macular degeneration services.

We found fragility of 'wet' AMD services is a major risk, due to the reliance on individual medical and administrative staff. When key personnel are absent parts of the care pathway cease working effectively. This generates backlogs which are difficult to clear. The Royal College of Ophthalmologists'[3] two-week referral to treatment target (RTT) is quickly breached with potential for avoidable harm to patients.

There appears to be a clear understanding across all health boards that further development of services is required to fully utilise available resources, including non-medical staff, to strengthen infrastructure and sustainability of eye care services. A greater proportion of consultant time should be focussed on the tasks that only they can do.

We saw several new initiatives across Wales relating to delivery of 'wet' AMD services. These included the introduction of non-medical injectors, and the development of Welsh Government (WG) funded pilot services within community based sites. These pilots were designed to increase capacity and provide more integrated services between primary and secondary care. However, progress in development and delivery of these initiatives has not been consistent across health boards.

Our review highlights the increasing demand on secondary care services. We saw some excellent examples of co-operation between primary and secondary care. In one remote area within Hywel Dda University Health Board, a system has been introduced involving optometrists undertaking regular assessments for stable patients, reducing the need for elderly patients to travel long distances and easing the pressure on hospital services.

[3] The Royal College of Ophthalmologists champions excellence in the practice of ophthalmology.

Also, within an optometry practice in Newport city centre, a service has been introduced involving optometrists providing a referral refinement service which has greatly enhanced the ability of consultants in secondary care to accurately triage suspected 'wet' AMD referrals. The success of these initiatives is reliant upon good communication and co-operation between staff in primary and secondary care.

We heard that poor working relationships between primary and secondary care in some health board areas have hindered efforts to improve joint working.

The Welsh Government has taken steps to address these issues, by requiring all health boards to establish an Eye Care Group and appoint an optometric advisor.

Eye Care Groups are chaired by a member of the health board executive team. Membership of the group includes clinical and managerial leads from primary and secondary care, the optometric advisor, the Community Health Council and local third sector organisations. They aim to provide a forum to discuss issues of concern, develop lines of communication, build trust and foster joint working initiatives. The role of the optometric advisor is to work with colleagues in secondary care to improve working relationships and facilitate initiatives to deliver more joined up services.

We were informed by primary and secondary care staff that relationships between these two sectors have improved. However, more work is required in many areas, for example better utilisation of Eye Care groups.

We heard concerns from health board staff about the lack of investment in the development of eye care services over the past few years. We were told that investment in services has not kept pace with the growing demand. As a result there is now a significant deficit in the capacity to deliver safe and timely care.

Recruitment and retention of medical and non-medical staff is an issue and a contributory factor to the fragility of services. We heard that more attention to workforce planning is needed. In particular, better succession planning is required for all staff groups. More thought should be given to providing opportunities for career development among non-medical staff mitigating the risk of overreliance on key members of staff.

We were told that health boards demonstrated little understanding of capacity and demand. The patient management systems used to actively capture data are inadequate; it is very difficult to extract useful information from them. Much of the subspecialty data presented to the Welsh Government National Planned Care Board[4] has been gathered by labour intensive processes which are unsustainable. There is limited data publically available specifically in relation to 'wet' AMD patients in Wales. Information available relates to numbers of overall opthalmology patients.

[4] Ophthalmology planned care board was one of four (others are orthopaedics, Ear Nose and Throat and Urology) established as part of the Welsh Government planned care programme. This programme has been set up to support health boards to improve patient experience by sharing good practice and creating sustainable pathways of care.

We conducted a range of interviews during the course of our review, receiving significant anecdotal contributions from a variety of stakeholders. Whilst clear themes emerged from the view expressed, we were disappointed at the availability of quantitative and performance data, to further explore and qualify these views. We have recommended that improvements are made to information management systems within health boards.

Health boards need better information about the demand capacity gap to enable informed workforce planning decisions. The allocation of resources should be dictated by patient need.

We found deficiencies in the ability to share clinical information across multiple sites. For example, in some areas it was reported that it was not possible to share clinical images between sites despite digital images being captured with the same brand of optical coherence tomography (OCT)[5] camera in two clinics. This causes difficulty for staff, results in duplication and impacts upon continuity of care, as well as the efficiency of the service. We heard concerns that the introduction of additional community based sites without the correct infrastructure may exacerbate this issue.

Health Boards should encourage clinical leadership, decide on priorities for development and ensure a unified approach. For example, the main imaging system should be consistent and networked across the health board to facilitate efficient service delivery.

The unsuitability of environments in secondary care from which services are being delivered from was consistently reported to us as an issue. We were told that the lack of space and facilities are limiting capacity to meet demands on the service. For example, a lack of clean room facilities to perform intravitreal injections was limiting the amount of injections that could be performed.

We heard that public awareness is an issue that requires more attention. Too often 'wet' AMD is first detected during a routine eye test, by which time vision may already be poor. The public need to be reminded of the importance of having their eyes tested regularly. They should look out for changes in central vision especially distortion, reporting any concerns promptly to an EHEW (Eye Health Examination Wales) accredited optometrist. There is a need for greater clarity around the services available for people with eye problems. In particular, the fact that EHEW examinations are free for people living in Wales who develop an acute eye problem and that there is no obligation to buy glasses.

Overall, our review highlighted a lack of leadership and focussed strategic planning within health boards to develop ophthalmic services. Most services have insufficient core capacity to meet demand. Progress has been made in some areas to strengthen service capacity and improve efficiency. Further focus is required to ensure that all health boards establish more sustainable, patient centred services.

[5] is a non-invasive imaging test that uses light waves to take cross-section pictures of your retina, the light-sensitive tissue lining the back of the eye

3. What we did

In 2015-16 HIW committed to undertake a thematic review of ophthalmic services across Wales. Due to the risks associated with any delay in treatment for patients with 'wet' AMD, it was decided that the review would be based around the 'wet' AMD pathway

We gathered information about ongoing work relating to delivery of eye care services. This highlighted that there had been a concerted effort to address issues in relation to demand, capacity, activity and backlogs. This work included the introduction of the National Ophthalmic Implementation Plan in 2015, as well as other initiatives which have been introduced within individual health boards. For example, the Clinical Prioritisation Project aimed at ensuring patients are seen in accordance with clinical need as opposed to a generic waiting time target (Referral to Treatment Time (RTT)).

Despite this work we learnt that patient waiting times within secondary care remain a significant issue.

As part of our review we considered progress that had been made in relation to the relevant sections of the National Ophthalmic implementation Plan across Wales. We looked at other initiatives introduced within health boards, to gauge whether care pathways are patient centred and efficient. Additionally, we reviewed how effectively health boards have utilised service integration to make the best use of the variety of expertise and resources available.

To assist our review we approached the Royal College of Ophthalmologists and College of Optometrists [6] to seek relevant expertise for our review team.

A stakeholder reference group was established as part of the review which included membership from Optometry Wales [7], Community Health Council (CHC), RNIB Cymru[8], General Optical Council[9] and the Welsh Government. This group was set up to ensure that relevant organisations were kept suitably informed with the plans and progress for the review, as well as to provide guidance and scrutiny to our review where necessary.

[6] The College of Optometrists is the professional, scientific and examining body for optometry in the UK, working for the public benefit

[7] Optometry Wales is the professional umbrella organisation representing all community optometrists, dispensing opticians and optometric practices across Wales.

[8] RNIB Cymru is Wales' largest sight loss charity, which provides a wide range of services and support to blind and partially sighted people across Wales, as well as campaigning for service improvements and to prevent avoidable sight loss.

[9] The GOC are an organisation which regulates optical professionals in the United Kingdom. They set standards, hold a register, quality assure education and investigate complaints.

The review was undertaken in two phases:

- Phase one consisted of discussions with senior representatives from each of the health boards with the overall purpose of building up an all-Wales picture of what the current pathway looked like in each health board area. This phase helped to identify the main 'bottleneck' issues and understand what service development plans were being produced in an attempt to improve services.
- Phase two consisted of additional, more specific interviews in three selected health board areas. These interviews were with those staff directly responsible for the delivery and coordination of the care and treatment to patients. The areas selected for phase two interviews were Betsi Cadwaladr UHB, Cardiff and Vale UHB and Hywel Dda UHB.

As part of phase two, we also held group discussion sessions with primary care optometrists to ensure that we could consider their views and opinions on the pathway.

We also worked with the Board of Community Health Councils (CHC) during our review. The CHC's undertook a National Ophthalmology Patient Experience Review during 2016 and the CHC's work was shared with us to allow for patient views to be incorporated into our report findings and recommendations.

We conducted a range of interviews during the course of our review, receiving significant anecdotal contributions from a variety of stakeholders. Whilst clear themes emerged from the views expressed, we were disappointed at the availability of quantitative and performance data, to further explore and qualify these views.

4. What we found

Patient Referrals

Referral Process

In Wales the vast majority of 'wet' AMD referrals are initiated by optometrists working in primary care. The current process is that 'urgent' referrals are faxed through to the relevant clinic via a rapid access form. Once the referral is received the patient will undergo further assessment in secondary care which will involve an Optical Coherence Tomography (OCT) scan and a fluorescein angiogram[10]. This information is then reviewed by a Consultant Ophthalmologist to establish the diagnosis. If the presence of 'wet' AMD is confirmed, the patient will be offered treatment, which involves medication being injected into the eye.

The Royal College of Ophthalmologist recommends that treatment for the 'wet' AMD should commence within two weeks of the initial referral. Once treatment has started the patient needs to be monitored at varying intervals dependent on the treatment plan and drug chosen by the consultant. Recent changes to the Ranibizumab (Lucentis)[11] licence allow for longer follow-up intervals in selected cases. If patients are not seen within the clinically recommended timescales, there is an increased risk of poor visual outcome, including legal blindness.

We were told by optometrists that in general the 'emergency' or 'urgent' referral system for patients works well. It was felt by the optometrists we spoke with that the majority of cases referred as 'wet' AMD suspects are seen quickly in secondary care for an initial assessment. However, problems do sometimes occur. For example, occasions where 'wet' AMD patients have suffered harm as a result of there being delays in them being seen within secondary care.

We found that part of the problem for the delay in patients being seen by secondary care related to the method in which referrals were sent through. We were told by optometrists that there is currently no way of them knowing whether referrals have been received and read by secondary care once they are sent. Therefore, once a referral is faxed it is typically followed up with a telephone call by the optometrist's receptionist to the relevant clinic to establish whether it has been received and to confirm an appointment has been made for the patient. However, this manual process of telephoning eye clinics is both time-consuming and inefficient, in many cases taking multiple phone call attempts.

[10] a fluorescent dye is injected into your arm. Pictures are taken as the dye passes through the blood vessels in your eye. This makes it possible to see leaking blood vessels, which occur in a severe, rapidly progressive type of AMD.

[11] a prescription medicine for the treatment of patients with wet age-related macular degeneration (AMD), macular edema following retinal vein occlusion (RVO), and diabetic macular edema (DME).

We also found issues in relation to general or standard referrals (non-urgent) which are being sent through to secondary care via letter. We were told that some of these referrals are being dealt with extremely slowly and again there is no way of knowing whether the letters are being received or read. For example, when cataract patients are being referred onto secondary care currently there is no way of logging the referral. We heard of some patients who have returned to the referring optometrist over a year later yet to be seen in secondary care. This is clearly not acceptable, given that the RTT target for cataract patients is 26 weeks.

The introduction of electronic patient referrals would be of benefit. As well as being a more efficient process, it should safeguard against the risk of referrals being missed or duplicated. There are plans for NHS Informatics Service (NWIS)[12] to progress this area. However, as part of our review we were informed that the implementation of electronic referrals is going to be delayed until there has been further progress made in relation to the introduction of electronic patient records.

There has been an electronic patient referral trial undertaken in all health board areas which was initiated by the Welsh Government through NWIS. There were eight optometric practices selected to take part in the trial. Each selected practice has had to contribute data and attend regular meetings with NWIS relating to the functionality of the electronic referral trial process. We hope that this pilot aids with the implementation of electronic patient referrals across Wales.

The CHC's National Ophthalmology Review highlighted that some patients felt they had not been provided with sufficient information regarding the reason for their referral. Given the emotional impact of potential sight-threatening disease, it is extremely important primary care staff ensure patients are provided with adequate information about their eye condition and the treatment pathway they are being referred onto.

Quality of Referrals

We found that the quality of the referrals sent to secondary care from optometrists is variable. In some cases, lack of relevant detail makes accurate triage difficult. Inappropriate use of the rapid access pathway including for other macular diseases exacerbates delays for true 'wet' AMD cases. This is particularly difficult for health boards in trying to provide one-stop services where diagnostic investigations and treatment are offered at the first visit. Despite some reports of improvement in the quality of referrals it was still felt to be an issue throughout Wales. In one are within Hywel Dda UHB for instance it was reported to us that around 50% of referrals being sent are not 'wet' AMD. These referrals have to be screened out at the first appointment following review.

[12] NWIS are the national organisation delivering technology and digital services for modern patient care in Wales.

In attempting to understand the reasons for these referrals ultimately deemed inappropriate by the consultant, our discussions with optometrists revealed that when the symptoms being displayed by the patient are indicative of 'wet' AMD (in the absence of an in-house OCT and relevant training/qualifications), they are clinically bound to refer the patient onto secondary care to investigate the presence or absence of the relevant symptoms.

The optometrists felt fully justified in this approach to prevent avoidable vision loss. If they are uncertain of the diagnosis their clinical priority is to safeguard the patient. Some cases of 'wet' AMD may report typical symptoms in the absence of obvious clinical signs. In these cases an OCT scan is very helpful.

Most optometrists in primary care do not have access to an OCT scanner. Those with a scanner felt that it helped them to reach conclusion more quickly in relation to patient symptoms, and allowed for a more informed decision about which patients need to be referred onto the rapid access pathway. A suggestion put forward to us was to amend the patient pathway to allow optometrists without OCT scanners to make a 'sideways referral' to another optometrist with access to a scanner. It was felt that this approach could reduce the demand on secondary care with fewer OCT scans needed within secondary care, and a reduction in the number of inappropriate and false positive referrals.

An 'acute macula' referral refinement system was recently introduced in Aneurin Bevan University Health Board. All suspected cases are referred directly to an optometry practice located in Newport City Centre. The practice is equipped with an OCT scanner linked to secondary care. Patients are offered an assessment within two days. The logMAR[13] visual acuity is measured and an OCT scan performed. An electronic referral is generated in every case for triage by a retina consultant within 24 hours. A letter is sent to the patient, copied to the referral refinement centre, the originating optometrist and general practitioner. The patient also receives an information leaflet explaining their condition and any proposed investigation/treatment. During the first six weeks of this scheme (October-November 2016) 36% of 'acute macula' referrals assessed did not require an appointment in secondary care, 31% went onto attend the rapid access clinic and the remainder were directed into a more appropriate care pathway in the eye clinic. The mean time from originating referral to first treatment for 'wet' AMD suspects reduced from 34.7 days to 15.9 days, with no patient waiting longer than 28 days to start treatment.

[13] A LogMAR chart comprises rows of letters and is used by optometrists, ophthalmologists and vision scientists to estimate visual acuity.

The introduction of this pathway required clarity on training, funding and equipment for optometrists taking on the role. The health board needed to be assured that optometrists had the required knowledge and experience to acquire images of diagnostic quality. An electronic system was created to transfer referral information from the refinement centre to the triaging consultant. To avoid unnecessary delays, several optometrists in the refinement centre were trained to use the OCT scanner and there is a system for cross cover between retina consultants triaging referrals within secondary care.

Health boards should consider introducing methods to address the number of inappropriate or false positive referrals received via the rapid access pathway. Consideration should also be given to the availability of scheduling training events/ seminars aimed at raising awareness of optometrists and other relevant staff.

Communication Following Referral

As highlighted above, there appears to be a lack of communication from secondary care once referrals have been sent. We learnt that this was an issue for all eye care referrals; however AMD services (rapid access) were felt to be particularly poor. In most cases, optometrists are only being updated on the action taken following the referral when the individual patient returns to the practice to see them again. This means that the optometrist is reliant on the patients' understanding on what they have been told about their diagnosis as well as any subsequent treatment that has taken place. Consideration needs to be given to methods of ensuring that referring optometrists are provided with updates on any subsequent diagnosis and treatment received by their patients.

Whilst there are legal requirements which state that letters have to be sent from secondary care to the patients GP in relation to their diagnosis and any treatment received. This information is not consistently being sent to the referring optometrist to update them. The Welsh Government's Welsh Health Circular[14] previously detailed that patient consent is required for this information to be provided to the optometrist, even if it was the optometrist who made the initial referral. However, the Caldicott review published in 2013 created an additional principle "The duty to share information can be as important as the duty to protect patient confidentiality". The review stated that "for the purposes of direct care, relevant personal confidential data should be shared among the registered and regulated health and social care professionals who have a legitimate relationship with the individual".

It appears that there is a lack of feedback to optometrists regarding the outcome or quality of referrals. Given the concerns raised by secondary care about the number of incorrect referrals being made, this type of feedback would be important in ensuring learning, as well as a mechanism to enable both improvement in the quality of referrals and a reduction in their numbers.

[14] WHC (2015) 022

We feel it is essential that feedback is provided to referring optometrists following every referral submitted to secondary care, to ensure that they are updated on any diagnosis and treatment. Feedback could also safeguard against the rapid access clinic slots being taken up by patients unnecessarily, by reinforcing the importance of the correct use of the pathway.

As previously mentioned, electronic referrals from optometry into secondary care would be a positive step to improve communication between primary and secondary care. Optometrists in Wales have been offered their own secure NHS email addresses which could facilitate this.

Additional issues highlighted as part of the CHC's review related to the information provided to the patients prior to their treatment. Patients felt that they had not been provided with sufficient information within secondary care prior to receiving treatment. It is vitally important that every effort is made by staff to explain the treatment procedure/plan with every patient prior to the treatment they receive, to ensure that there is informed consent.

Treatment and Monitoring

Treatment Timescales – Initial treatment

When confirmation of a 'wet' AMD diagnosis is reached, arrangements should be made for the patient to receive treatment as soon as possible. Royal College of Ophthalmologists guidance states that the current Referral to Treatment (RTT) for treatment following the initial referral is two weeks. The majority of health boards are running two-stop clinics. Patients attend the clinic for an initial assessment and investigations. If further investigation and/or treatment is required a second appointment is arranged. Some areas have adopted a one-stop clinic approach where assessments, investigations and the first treatment (if required) are completed on the same day.

Performance against the two-week target (RTT) was consistently reported to be a challenge by health boards. We saw that there is difficulty in triaging patients and booking them in for their treatment appointment within the two week timescale. This is why some areas have adopted the 'one stop clinic' approach.

We were informed that waiting times for initial treatment did reduce dramatically following the introduction of the Rapid Access Clinics; however, the success of these clinics relies upon the quality of the referrals they receive. False positive referrals reduce the efficiency of the clinics. Performance against the target for initial treatment varies between areas. What is clear is that performance against this target is very inconsistent and fluctuates considerably throughout the year.

Treatment Timescales – follow-up treatment

At the time of diagnosis, the retina consultant will come to a decision regarding the best drug and treatment regime. The initial loading phase of treatment is similar for Ranibizumab (Lucentis) and Afibercept (Eylea)[15] involving three treatments at four week intervals. Thereafter follow up intervals vary. Historically, the patient reviews and subsequent treatment for 'wet' AMD patients has been provided by consultants or staff grade doctors.

We learnt that there are capacity issues in relation to on-going treatment. Most health boards have a backlog of patients resulting in extended follow-up intervals.
A combination of two main strategies have been employed to maximise outcomes whilst minimising demands on the service.

Afilbercept (Eylea) was approved by the National Institute of Health and Care Excellence (NICE) in July 2013. The treatment regime involves three loading doses at four-week intervals followed by eight-week follow-up with treatment at every visit during the first year. In the second-year monitoring continues at eight-week intervals but treatment is only administered if there is evidence of active disease.

The second strategy relates to the Ranibizumab (Lucentis) 'Treat-and-Extend' protocol. The schedule of Product Characteristics (SPC) for Ranibizumab was amended in September 2014, removing a requirement for four weekly follow-up visits. With this protocol the patient receives three loading doses at four week intervals and is then reassessed four weeks after the third treatment. If the condition appears inactive, treatment is administered and the interval to the next appointment is extended by two-weeks usually subject to a maximum of 12-weeks. If the condition appears active, treatment is administered and the interval to the next follow-up is reduced by two-weeks subject to a minimum interval of four-weeks. The treatment cycle continues until there has been no sign of active disease during three visits at 12-week intervals. The aim of this model is to tailor treatment to clinically determined disease activity.

It is vitally important that follow-up intervals specified by consultants are both recorded and followed for optimal results. Health boards should have a system for recording variance between medically recommended follow-up intervals and actual follow-up intervals. This data should be regularly monitored and used to ensure capacity keeps pace with demand.

The problem with providing timely ophthalmology follow-up appointments is not limited to 'wet' AMD treatment. During the course of this review we saw that an alternative Clinical Prioritisation model had been adopted in two health board areas to manage the potential risks associated with ophthalmology follow-up backlogs. The model involves stratifying all patients (new and follow-up) according to clinical need as opposed to generic referral to treatment time targets (which priorities new over follow-up patients). Patients at risk of permanent sight loss (for example retinal detachment, 'wet' AMD, diabetic retinopathy and glaucoma) have the highest clinical priority (P1) and would

[15] is a prescription medication administered by injection into the eye for treatment of patients with Wet AMD, Macular Edema, Diabetic Macular Edema (DME) and Diabetic Retinopathy (DR)

always be seen first. Patients at risk of reversible sight loss (for example cataract) have medium priority (P2) and would be seen if there are no P1 cases waiting. Patients with no risk of permanent sight loss (for example benign eyelid lesions, watery or irritable eyes) have the lowest priority (P3) and theoretically would not be seen until there were no patients with higher priority waiting.

We learnt that there are differing views amongst consultants and health board managers about the practicality, efficiency and sustainability of the Clinical Prioritisation models. Whilst P1 patients are seen promptly, P2 and P3 patients wait lengthy periods with a predictable impact on RTT targets. Some cataract patients have been waited up to 52 weeks for treatment.

Our review has highlighted the need for change to create sustainable eye care services to meet growing demand. In line with the principles of Prudent Healthcare [16], care should be provided for those with the greatest health needs firsts, making the most effective use of all skills and resources available. This will involve changing some established working practices. It is the responsibility of health boards to determine which approaches are utilised to provide follow-up treatment to patients.

Treatment Timescales – targets

We heard concerns from health board staff in relation to the RTT target itself. We were told that while the initial two-week target was helpful and beneficial to patient care, there has previously been no set monitoring or ongoing targets in relation to follow up patient care. However, as part of our review we were informed by the Welsh Government that health boards now have to report on follow up patient care.

We feel that it is important that there is more focus from the Welsh Government and health boards on patient outcomes. The Royal College of Ophthalmologists (RCO) recently published their "Three Step Plan" which sets out to ensure that follow up patients are prioritised in the same way as newly referred patients, to ensure that health board systems monitor and report on any follow-up appointment delays. The RCO recognise that follow up patients are "8-9 times more likely to have a sight threatening condition that needs long term monitoring".

Concerns were raised by staff within Cardiff and Vale University Health Board and Abertawe Bro Morgannwg University Health Board relating to the priorities of the health board management in their areas. The view was expressed that these health boards have prioritised meeting referral to treatment time targets above clinical need for eye care patients. We were told of occasions within CVUHB, when lower risk patients were actively prioritised for appointment slots above those at higher risk of harm. These decisions had been instigated by management overruling clinical views to prevent lower risk patients from breaching an arbitrary RTT target. If this represents a systemic policy it would be cause for serious concern. Health boards must ensure, insofar as it is possible, that patients are treated according to clinical need.

[16] http://www.prudenthealthcare.org.uk/principles/

We also heard concerns around some of the approaches being used by the Welsh Government and health boards to reduce waiting times. These include offering financial incentives to health boards meeting RTT targets, running weekend clinics and outsourcing patients. It may be more effective to concentrate efforts and resources on developing the way services are delivered to maximise capacity. The goal must be to create robust and sustainable services capable of scaling up to meet future demographic challenges, as opposed to spending resources on short-term strategies.

Incident Reporting

Welsh Government has a policy in place which states that where harm occurs to a patient as a result of patients waiting longer than the recommended treatment time to be seen, that the relevant health board must submit a Serious Untoward Incidents (SUI) to the Deputy Chief Medical Officers' Department for consideration. This information is then reviewed and presented to the WG Quality and Safety group monthly meeting.

We found there to be a lack of awareness in the majority of areas in relation to this requirement. Only those we spoke to at Cwm Taf UHB were able to describe in detail the policy/process for reporting SUI's to WG. In other areas there was a lack of awareness of the requirement to report incidents and how to do so.

The majority of those we spoke to explained that whilst incidents are reported via Datix[17], most were unsure about any subsequent action taken by their health board and that they did not receive any feedback in relation to these incidents.

Whilst we have seen correspondence which has previously been circulated to all health board Medical Directors by the Deputy Chief Medical Officer to remind Ophthalmology staff of their responsibility to report any incidents in which harm has occurred. To assist staff, the previous correspondence circulated has also included information defining 'harm' from guidance issued by The Royal College of Ophthalmologists.

Royal College guidelines for the management of age-related macular degeneration 2013 do not define what constitutes a reportable serious incident other than endophthalmitis (a severe infection of the eye). In 2015, the British Ophthalmology Surveillance Unit (BOSU) survey of patients losing vision due to delayed follow-up requested details of patients losing more than 15 logMAR letters (moderate visual loss) or 30 logMAR letters (severe visual loss) from one visit to the next. These definitions have been adopted by Welsh Government in relation to serious untoward incident reporting. Reporting such incidents is an important way to highlight issues within an organisation.

Health boards must ensure that when incidents occur, Serious Untoward Incidents (SUI) reports are submitted, in accordance with Welsh Government policy relating to patient harm. Health Boards must have mechanisms in place to review incidents to spot potential patterns providing early warning of more serious systems failure. When systems failure is detected health boards must provide timely and effective support designed to address underlying issues.

[17] Patient safety software and risk management software systems for healthcare incident reporting and adverse events.

Treatment – Capacity

A key consistent theme emerging from our review has been the deficit between the capacity available and the growing patient demand for ophthalmology services.

We saw that the ability of services to address the backlog of follow-up patients was as great a problem as meeting the initial RTT target. The fragility of services appears to be a major risk, mainly due to an over-reliance on individual medical staff causing delays in patients being seen. A significant proportion of consultant's working time in a traditional treatment clinic is occupied with tasks that can be performed effectively by other members of the multidisciplinary team. Medical staff working alone cannot meet all the demands on the service. The resilience and capacity of services would be strengthened by improved multidisciplinary team working.

In all the health board areas that we reviewed recruitment and retention of staff at all levels (consultants, middle grade staff and admin staff) was reported as a concern. We were provided with a number of examples of the detrimental effect this has had on capability and performance. There needs to be more focus from health boards in developing workforce plans that mitigate the risk of patient care being affected by recruitment and retention issues.

We heard concerns and frustrations from secondary care around the perceived lack of investment in services in recent years. It was felt that investment in services has not reflected the growing demand. For example, concerns were raised by both primary and secondary care staff in relation to the insufficient investment in the service in Wrexham Maelor Hospital. We were told that a consequence of this was that the service was both understaffed and extremely fragile. Furthermore, the optometrists we spoke to from north central and north east Wales told us that they routinely send their 'urgent' referrals to the Abergele Eye Clinic as opposed to Wrexham as they believe their patients will get seen a lot quicker. Whilst those we spoke with in Wrexham told us that their concerns had been escalated to management within the health board; they told us that there has been no action taken to address the issues within the service so far.

Treatment – Initiatives to improve capacity

We feel that health boards need to place more emphasis assessing available skills and capacity in order to identify initiatives that may aid with remodelling the way in which services are being provided.

One such initiative that is being implemented across Wales to increase capacity of services is the introduction of non-medical injectors. Historically, patient injections have been administered by either consultants or staff grade doctors. The introduction of non-medical injectors is intended to reduce the burden on the medical staff and mitigate the risk of bottlenecks from occurring in relation to patient treatment. Before non-medical injectors are able to take on their role unsupervised, they are required to carry out 100 supervised injections alongside a consultant.

We saw that there has been varied progress made in relation to the introduction of non-medical injectors across health boards. For example, Cardiff and Vale and Aneurin Bevan University Health Board's have a number of non-medical injectors (four nurse injectors each) responsible for undertaking a significant proportion of intravitreal treatments. The introduction of these non-medical injectors has had an extremely positive effect on service capacity and there are plans for further expansion of the service.

However, other health boards have not made similar progress with non-medical injectors. Many staff in these areas expressed frustration regarding the lack of progress. We were told that there have been problems backfilling posts and a lack of clarity around arrangements for indemnity. In Betsi Cadwaladr UHB, the issue of indemnity for nurse injectors has delayed progress by around 18 months. Whilst these issues have been resolved, we were informed that funding for these roles has only been secured for 12 months.

We feel that it is important that health boards consider the benefits of introducing non-medical injectors. They have proved to be very effective and beneficial resource to those health boards who have introduced them. Health boards should learn from the experiences of both Cardiff and Vale and Aneurin Bevan Health Boards in attempting to introduce this initiative.

We feel that more consideration needs to be given by the Welsh Government in developing approaches to encourage shared learning between health boards as well as more integrated methods to address common themes/issues being experienced across Wales.

The Welsh Government's Planned Care Programme was established to support health boards to improve patient experience by sharing good practice and creating sustainable pathways of care. Given the apparent inconsistencies in the progress that has been made across Wales regarding the introduction of non-medical injectors, we feel that health board Clinical Leads should be encouraged to utilise the Planned Care Board to seek advice from other areas.

Service Support Staff – AMD Coordinators

A number of health boards have appointed designated AMD Coordinators whose main role is to coordinate the service by booking in patients for their follow-up appointments. We heard that AMD Coordinators provide an invaluable contribution and improve the efficiency of services. In some areas the AMD Coordinator is also responsible for collating data relating to patient treatment to establish performance and finance figures. This information has to be supplied to WG Planned Care Board and the health board Finance Team on a monthly basis.

We heard that if inadequate cover is provided when the AMD Coordinator is away from the service, it can quickly become disorganised. This has a direct impact of the effectiveness of the service.

The AMD Coordinators we spoke with explained that the data collection element of their role can be extremely time consuming, primarily due to the inconsistent methods in which information is being recorded. One AMD Coordinator told us that that this task alone took up more than half of the role. We believe that all health boards should give consideration to appointing an AMD Coordinator. Furthermore, health boards should ensure that individuals undertaking the role are adequately supported and that sufficient cover exists during periods of absence. Health boards may even consider appointing more than one AMD Coordinator. The success and efficiency of a service should not be wholly reliant upon one individual role.

Service Support Staff – Eye Care Liaison Officers (ECLO)

We saw the valuable contribution that the Eye Care Liaison Officers (ECLO) provide to patients following referral and confirmation of diagnosis. The ECLO's are responsible for providing emotional support, as well as advice and information to help patients understand their condition and treatment plan. They are also able to identify and link with any other support required for the patient, for example, social services. ECLO's are able to spend a greater amount of time with the individual patient answering any queries/concerns they may have, which frees up consultant time.

Funding for the ECLO role varied in the three areas we visited as part of phase two of the review. In Hywel Dda UHB funding for the ECLO role is provided by Sight Cymru[18]. In Cardiff and Vale UHB the role is funded by RNIB Cymru and in Betsi Cadwaladr UHB the role is funded wholly by the health board

ECLO's cover all eye care services, and whilst there is currently no formal referral process to an ECLO, informal referrals are received from other staff within the service on an ad-hoc basis. ECLO's may also review patient notes themselves to determine whether support may be required for the individual.

We learned that ECLO's had concerns that patients are being asked to attend eye clinics following referrals, but are unsure as to the reason why they have been referred. As previously stated, this issue was also raised as part of the CHC National Ophthalmology Patient Experience Review.

Furthermore, ECLO support is not being fully utilised by all health boards. This may be because not all secondary care staff are aware of, or recognise the role offered by the ECLO and the benefits this role offers patients. More focus needs to be given in educating staff on the benefits the ECLO service offers. In response to their under use, we heard that some ECLO's have resorted to knocking on the doors of staff including consultants to try to ensure that they are aware of and are fully utilising the support available for patients within the service. Clearly this aspect of the service needs improvement in order to improve the patient experience.

[18] Sight Cymru is an independent Welsh sight loss charity.

We were told of the concerns that ECLO's have in being able to provide the required level of emotional support and advice to patients. For example, we were informed that in Abergele there is 32 hours of ECLO time spread over four days a week, which was not felt to be sufficient in terms of the support required for patients. Concerns were also raised in relation to the lack of cover available for the ECLO role, where staff are away from the service, on leave etc. This means that there are occasions where emotional support and advice is not available for patients.

We also learnt that non-medical/support staff experience frustrations in raising concerns within their organisations. Where concerns have been raised with Directorate Leads they have subsequently received very little in terms of feedback. This has resulted in staff not feeling empowered to make suggestions for improvements. Health boards must ensure that there are mechanisms in place to ensure staff are empowered voice their views/ concerns with senior staff and that feedback is routinely provided to them.

Suitability of Environment

We saw that another aspect which impacts the capacity and capability of services to meet growing demand is the suitability of the environments where the eye clinics are provided. We consistently heard concerns from all health boards in relation to the insufficient space and facilities available to deliver services. These issues were impacting on the capability and capacity of the service of meeting the demands of the service. For example, in the Hywel Dda UHB North Road Clinic there has been a restriction placed on the daily intake of patients due to concerns highlighted by Health and Safety in relation to the layout and lack of space within the clinic. Staff at the clinic told us that did not feel that the building was fit for purpose. Whilst we are aware of the health board's plans to develop the estate, we were also told that these plans have been ongoing for two years.

The rurality of services in some health boards, particularly Hywel Dda and Betsi Cadwaladr UHB's is also an issue for patients. This issue was also highlighted as part of the CHC National review. Some patients have to make three-hour round trips to attend appointments at their relevant eye clinic. Given the fact that the majority of 'wet' AMD patients are elderly, this obviously causes issues for them and other family members.

As a result there have been additional services introduced in several areas including a 'one stop clinic' being provided from a GP practice in Crymych, part of Hywel Dda UHB. The introduction of this service has meant that patients within the area now do not have to travel long distances to attend their appointments. The health board are planning to set up similar arrangements with other practices in other areas in the future.

Every health board provided proposals to the Welsh Government to implement their own WG funded pilot service. However, only four health boards were successful. These were Aneurin Bevan UHB, Cwm Taf UHB, Hywel Dda UHB and Powys THB. We were informed that there are plans to independently evaluate each of the pilot services after a year to determine its effectiveness.

Service Development

In July 2015, health boards were asked by Welsh Government to submit bids for pathfinder funding of pilot services to treat 'wet' AMD in a primary care setting. These pilots were originally funded with a timescale to be up and running by April 2016. Welsh Government was deliberately not prescriptive about the requirements because it was felt important for each health board to establish a service bespoke to the needs of its patients.

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One of the pilots is a primary care based Ophthalmic Diagnostic and Treatment Centre (ODTC) in Aneurin Bevan University Health Board. This one-stop service is being delivered from an optometry practice in Newport city centre close to the bus station and car parks. At present, it is wholly staffed from secondary care but optometrists in the practice have observed and worked with medical photographers to get practical experience of performing OCT scans. Consultants review the images and when necessary treatment is provided by a non-medical injector within the ODTC itself.

Where services have outgrown existing accommodation, expansion into a community/ primary care setting is a positive step for patients and consistent with the principles of prudent healthcare. Adequately staffed and resourced these facilities will reduce pressure on other parts of the hospital eye service. Concerns were raised about secondary care staff providing exactly the same service from a primary care setting.

The role of the Optometrist

In Wales Optometrists who wish to provide NHS treatment/monitoring for patients have to be EHEW (Eye Health Examination Wales) accredited. This is an enhanced qualification undertaken following an optometrists' initial three year degree. EHEW accreditation is achieved by online distance learning as well as Objective Structured Clinical Examinations(OSCEs). Completion of these requirements results in the optometrist being accredited to provide an enhanced service.

Once accredited there is a requirement that professionals will attend compulsory training every three years. This training focuses around themes pertinent to the current eye care issues and/or resulting from the findings of clinical audits. EHEW undertake audits every year.

The vast majority of eye examinations conducted within optometric practices qualify for an NHS fee. The WECS (Welsh Eye Care Services) funding was previously held centrally by the Welsh Government. However, with effect of April 2016 the WECS funding was devolved back to the control of the health board, which meant they will hold the responsibility for clinical governance of optometrists providing NHS care.

The optometrists we spoke with felt that their role was evolving. They are becoming more involved in joint schemes with secondary care and feel that additional responsibility is being allocated to them through WECS referrals. The additional activity that has been allocated to them through WECS has also brought with it extra responsibility and risk. An optometrist cannot 'cherry pick' the WECS activity they wish to carry out, which means there is a lot more pressure in undertaking the role than there used to be, due to the increase in healthcare patients alongside commercial requirements. We were informed that some optometrists have decided to deregister from providing WECS due to the demand and stress caused by the additional role. For example the emergency appointments referred to them via WECS.

The optometrist group discussion sessions we held highlighted that due to the evolving role, there may become a point where optometrists have to decide whether they want to provide healthcare or pursue a more commercial route.

The majority of optometrists we engaged with felt that there were opportunities to remodel the way in which services are being provided to increase capacity and address waiting time issues. Optometrists felt under-utilised and are keen to become more involved in decision making as well as providing follow-up reviews of stable patients, including AMD and Glaucoma patients. A lot of consultant time is being taken up reviewing these patients and there may be an opportunity for optometrists to take on more of a role. This would allow for consultant/medical staff time to be better utilised in focusing on higher risk patients.

To enable more effective utilisation of optometrists, there are other aspects that require greater clarity if the role of the optometrists is to be utilised fully, these include:

- Indemnity protection for optometrists
- Capacity/resource arrangements, to ensure that primary care providers are able to fully meet the WECS requirements
- Finance arrangements for undertaking the additional roles through WECS. For example, for OCT equipment.
- Qualification/training – it was felt that there needed to be more opportunities for more in depth development training to ensure that community optometrists are able to provide hospital standard care to patients. For example, from consultants within the same area. It is of note that various optometrists practicing in Wales are undertaking diplomas in medical retina, including the management of AMD and using OCT scanners. This will provide a source of non-medical AMD practitioners in the near future in Wales.
- Communication mechanisms need to be improved between primary and secondary care. For example, referrals and the sharing of patient information.
- It is notable that there are few hospitals optometrists in Wales compared to other areas of the UK, where hospital optometrists are common place in eye units.

Utilisation of Optometrists

During our discussions with the Welsh Government we were informed that in September 2015, there were between 4000 and 10000 patients per health board waiting to be seen by Consultants. Improved working relationship between primary and secondary care could be invaluable in dealing with this backlog of patients. We have found that the additional utilisation of optometrists to strengthen available capacity has varied across health boards thus far and is an area that requires attention by all health boards.

Progress with the use of optometrists has been predominantly over-reliant on the views and engagement of the consultants within the relevant health board area. For example, we learnt that a consultant in Hywel Dda UHB has agreed a plan with the health board to revamp the way in which stable AMD patients are being reviewed. This plan aims to take advantage of the huge resource potential provided by community optometrists to undertake stable patient reviews.

The implementation stage of this initiative has involved the consultant spending time working alongside the selected optometrists within their practices to ensure that they each receive the required level of support and training to ensure that they become adequately skilled and confident enough to carry out these reviews independently. Phase one of this initiative has involved 60 patients being outsourced to five optometric practices involving seven optometrists within four different towns within Hywel Dda UHB. There are plans for the health board to extend these plans further.

It is hoped that this initiative will mean that the optometrists involved will undertake around 25% of stable patient reviews for the consultant. We were informed that for every 18 decisions that are made by optometrists as opposed to the consultant ophthalmologist, it would equate to one free clinic session for the consultant.

In addition to this initiative, the same consultant has been working with one optometrist to trial another new approach to providing review clinics for all intravitreal service patients (AMD, retinal vein occlusions and diabetic macular oedema).

The optometrist has spent time working alongside the consultant within secondary care to develop the required knowledge/skills to review patients. This arrangement has progressed to the point where the optometrist now carries out review clinics on behalf of the consultant, which again has meant the consultant's time has been freed up to focus on other activity, which has included weekly theatre sessions to undertake patient treatment.

There has been a further development with this initiative which means an additional optometrist has now become involved and there are now plans for these two optometrists to undertake the consultant's review clinics for all of his patients every Monday and Wednesday.

The approaches taken in Hywel Dda appear to have been successful in freeing up consultant time and opening up service capacity. However there has been less progress in the majority of other health board areas relating to the utilisation of primary care optometrists.

In attempting to understand the reasons for this we learnt that consultants held mixed views on the additional use of optometrists. Some felt that optometrists offered a huge resource potential, whereas others had reservations as they felt that optometrists do not have the required level of knowledge and skills to take on the additional responsibility. In one area this has meant that a consultant was previously refusing to accept any referrals from optometrists despite it being the nationally agreed pathway.

The introduction of a WG policy (with effect of 1st March 2016), specified that patients with low risk of ocular hypertension[19] (not requiring therapy), with glaucoma suspect[20] status and following routine uncomplicated cataract surgery were to be discharged to primary care for follow-up reviews. We learnt that there were consultants who failed to follow this policy, due to them having concerns about capability of optometrists to carry out the role and their concerns around patients 'falling through the gap' within primary care, and issues surrounding communication of patients records.

The Wales Low Vision Services is another approach which attempts to utilise optometrists. These services are led by accredited low vision optometrists within the community. Once a patient is referred for an assessment the relevant assessments and paper work are completed by the optometrist. If the patient meets the required criteria, the patient then needs to be seen by a consultant for review, and to register the patient as sight impaired. Once the patient is registered they are able to access a care package which offers more support to deal with their impairment.

Concerns were raised about the efficiency of this approach due to the delays relating to the time it takes for the consultant to register the patient as sight impaired. We learnt that there have been occasions where patients have had to wait up to nine months for an appointment with a consultant. This has a clear impact on patients as they unable to access the support/care package available to them until them have been certified.

It may be worth exploring whether optometrists could be used to certify patients, which would mean that patients are able to access their required support sooner. This would also have the benefit of freeing up consultant time to focus on higher risk patients.

An additional concern raised by optometrists in relation to low vision assessments was that patients are not consistently being referred for an initial low vision assessment by secondary care staff. This means that some patients who may have registrable sight impairments will not be able to access the available support.

Primary and Secondary Care Relationship

HIW believes that poor relationships between primary and secondary care in the majority of health boards has hindered possible progress in development of more integrated services. This appears to be predicated upon the negative views of a small cohort of consultants about the ability of optometrists which has resulted in a 'frosty' relationship between primary and secondary care. Whilst we also heard that in general relationships had improved over the past few years, this issue continued to prevent effective delivery of integrated services.

[19] Ocular hypertension is when the pressure inside the eye (intraocular pressure or IOP) is higher than normal.

[20] The term glaucoma suspect describes a person who does not currently have glaucoma, but one who might be at risk of developing glaucoma.

To improve the working relationships between primary and secondary care, as well as to encourage more focus on integrated working initiatives, the Welsh Government has previously introduced two requirements for all health boards. The first was for health boards to establish their own local Eye Care Group. This group was to include clinical and managerial representatives from primary and secondary care, the Community Health Council and local third sector organisations. They are aimed to provide a forum to discuss issues of concern, develop lines of communication, build trust and foster joint working initiatives. The second requirement was for all health boards to recruit an Optometric Advisor, whose role it would be to work with colleagues within secondary care to improve working relationships and facilitate the introduction of initiatives to deliver more joined up services. At the time of our review, every health board with the exception of Betsi Cadwaladr, had successful recruited a permanent Optometric Advisor into post.

The health boards which had recruited Optometric Advisors felt that there had been a very positive impact in the relationship between primary and secondary care staff following the introduction of the role. However, further improvements were required to enhance the working relationships and initiatives being introduced. For example more opportunities for optometrists and ophthalmologists to spend time training/ working alongside one another in each of their own respected areas to build up clinical experience, knowledge and awareness of roles as well as building on working relationships.

Overall, we were informed by primary and secondary care staff that relationships have improved. However, further progress is required in many areas, for example better utilisation of Eye Care Groups in some areas.

Discharging Patients

Discharging Patients – criteria

A key issue that we found during our review related to effectiveness of patient discharge from secondary care. We found that in the majority of areas there are very few 'wet' AMD patients discharged from secondary care once they have been referred. We were told that health boards had policy/criteria available to determine whether a patient was stable enough for discharge; that a patient can be discharged if they have not received/ needed treatment in the past 12 months.

Royal College Guidelines (2013) state that permanent discontinuation of treatment should be considered if:

- best corrected visual acuity in the treated eye drops below 15 letters (1.40) on three consecutive visits despite optimal treatment
- there is a reduction of best corrected visual acuity by 30 letters or more compared either to baseline or best recorded level since baseline

The Guidelines go on to recommend that discharge should be considered if:

- a decision to discontinue a licenced anti-VEGF agent permanently has been made
- if there is no evidence of other ocular pathology requiring investigation or treatment
- there is a low risk of worsening or reactivation of 'wet' AMD (e.g. very poor central vision and a large non-progressive, macular scar).

In Aneurin Bevan University Health Board any patient whose first treatment was more than two years ago, and last treatment was more than one year ago, is discharged to the retina clinic for full ophthalmic assessment prior to a decision regarding final discharge. Patients are given a leaflet explaining symptoms to look out for, a contact telephone number and encouraged to contact the clinic directly in case of any problems. Since 2009, 55 (16%) of patients discharged with inactive lesions according to these criteria have restarted treatment for the same eye.

Following our discussions with staff we have concerns that there is potentially a lack of consistency in applying discharge criteria. This may result in patients being followed up unnecessarily or treated with little chance of benefit. This clearly impacts on demand for secondary care services. Health boards must ensure that there is a discharge policy in place, in line with Royal College Guidelines (2013), and that relevant staff are reminded of the importance of following the policy.

There is potential for some stable patients to be discharged for routine monitoring in primary care, releasing capacity in secondary care. This would ensure that consultant time is focussed on managing higher risk patients.

As previously mentioned, from 1st March 2016 a new Welsh Government (WG) policy was introduced for discharging patients following routine uncomplicated cataract surgery, those with low risk ocular hypertension not requiring therapy and those with glaucoma suspect status into primary care for follow up reviews. The aim being to reduce the burden on secondary care by utilising the available capacity offered by optometrists. In order to provide these new services optometrists had to attend one of the events across Wales incorporating training on cataract and glaucoma to ensure that their knowledge was current. However, following the introduction of the policy was met with reluctance from consultants in some health boards. Again this relates to concerns from some consultants regarding the capability of optometrists to carry out the required roles.

Discharging Patients – quality of information

We heard concerns in relation to the lack of information available to optometrists when a patient attends their practice following discharge from secondary care. The current process is that patients are discharged with documentation to take with them when they visit their optometrist. It appears however that this does not routinely happen, and optometrists have to rely on the patient's memory/understanding of the treatment they have received and what they were told by their consultant regarding monitoring to determine the action required. This is clearly not acceptable and has the potential for key information not being provided to the optometrist.

There needs to be more focus on improving the information available to optometrists for patients that have been discharged. Optometrists told us that it would be extremely useful to have access to information on diagnosis and treatment provided to help them determine the level of monitoring required. It would also reduce the chance of unnecessary re-referral back to secondary care. The information provided to the optometrists should also include confirmation as to whether the patient has been registered as sight impaired.

In terms of addressing this problem, one suggestion put forward to us was for consultants to discharge to a specific optometrist, which could be the patients' preference. This approach would allow for the consultant to contact the selected optometrist via letter or telephone to update them on the diagnosis and treatment as well as the level of monitoring required. This approach could also aid in building working relationships between primary and secondary care. This solution, or any other proposed solution would have to be considered in line with the WECS requirements/ arrangements however. The introduction of an electronic patient record accessible in primary as well as secondary care could also assist with issues such as access to relevant information regarding patient status and history.

Information Management Systems

Information Management Systems – Planning

A consistent issue that emerged during our review related to information management systems. Information appears to be captured in different ways within the same health board areas. This impacts the ability to accurately collect data in relating to patients being seen/treated by services. For example, we were told that in some areas information is being recorded on paper which means that the only way to undertake any audit of patients treated is for a member of staff to physically trawl through the paper documentation.

It was felt by staff that consistency in data collection was an area which required more attention. In todays' digital age the collation of data on paper only leads to a multitude of issues, not least information security.

We heard that the IT software available within health boards was a concern. It was felt that the software available was not adequate to capture and extract data required for effective operational management of services. For example, the lack of ability to effectively report and analyse capacity and demand information. As a result there is very limited understanding within health boards of capacity and demand data currently.

Health boards are required to submit data for each of the main care pathways including AMD to the WG Planned Care Board on a monthly basis. The information includes capacity, number of referrals, new treatment stats, follow-up appointments and treatments. Given the IT issues highlighted above, this has proven to be an extremely difficult and labour intensive process and we were informed most health boards rely on manual data extraction to obtain at least some of the information.

All health boards need a far more detailed understanding of capacity and demand data to manage ophthalmology services effectively. A system to automate collection of this data would facilitate informed workforce and strategic planning around changes to existing services and implementation of new ones. It is only by quantifying demand-capacity gaps that resources can be fairly allocated according to patient need.

Information Management Systems – Sharing information

The IT systems currently available within health boards are not equipped to effectively share clinical information between multiple sites. This can cause problems for the services. An example provided was in relation to OCT scans, where there are issues when trying to view OCT images as they cannot always be shared across different health board areas due to networking issues. This causes difficulty for staff, results in duplication and impacts upon continuity of care, as well as the efficiency of the service. We heard concerns that the introduction of additional community based sites may exacerbate this issue

We believe that greater emphasis needs to be placed on improving access to information so as to improve efficiency of secondary care services across multiple sites, as well to ensure that the community based initiatives being introduced are not hindered by lack of access to patient information. Improvements in the capability of information sharing would also aid the utilisation of additional use of primary care optometrists.

During our discussions with staff we were informed that meetings have been held between relevant staff and NWIS to attempt to enhance the information sharing mechanisms available to staff.

As highlighted in a previous section, there needs to be more focus in relation to the introduction of electronic patient records and electronic patient referrals. We were told that there are plans by WG to progress with electronic referrals and optometrists felt that the recently provided NHS email addresses could be utilised in progressing with this.

Public Awareness

We believe that increased public awareness of 'Wet' AMD is required. This needs to include the symptoms to look out, associated/linked eye conditions, and the importance of seeking advice, from the relevant healthcare professional, quickly. There are concerns that some patients are waiting too long to seek help which given the risks of irreversible eye damage with the more serious conditions, could have detrimental impact on their eyesight.

The public perception of optometrists needs to be changed. The majority of people associate optometrists as more of a commercial profession than healthcare. An increase in the awareness of all services available to deal with eye care related issues could also mean a reduction in the patients attending secondary care unnecessarily.

More needs to be done to manage the expectations of patients once they are referred onto the 'Wet' AMD pathway. Issues were highlighted as part of the CHC National Review in relation to continuity of care, i.e. patients seeing different healthcare professionals as part of their care. Most patients believe that the consultant is the best person to speak to, however, this may not always be the case and given the changes to the service pathways that are being introduced. Patients need to be made more aware of the other professionals who are able to monitor/treat them in relation to their eye healthcare included nurses and optometrists.

5. Conclusion

The aim of this review was to identify any issues in the delivery of the 'wet' AMD pathway and to highlight examples of good practice. It is clear to the review team that many of the lessons learned can be applied more broadly to other aspects of the ophthalmology service.

It is almost ten years since the first intravitreal injection for 'wet' AMD in NHS Wales. Newly appointed consultant ophthalmologists have no direct experience of a time without an effective treatment for what is the most common blinding disease in Wales. Despite the challenges facing services and documented in this report, many patients continue to benefit from treatment, retaining much better vision, quality of life and independence than was thought possible before. We acknowledge the dedication and hard work of multidisciplinary teams across Wales who make this possible, sometimes working in difficult conditions.

The two-week referral to first treatment target is a significant challenge. It is difficult for optometrists in primary care to detect early signs of 'wet' AMD and there is a tendency to err on the side of caution. A referral refinement system to include logMAR acuity and OCT scan, reviewed by one of the retina team, can reduce the number of urgent appointments and maximise efficiency of Rapid Access Clinics in secondary care.

Intravitreal therapy services are still expanding rapidly, outgrowing facilities and stressing the systems around them. Demographic projections[21] indicate that this trend will continue for the foreseeable future. All intravitreal services must have a realistic plan for future expansion. There is a long lead-in period for developing new treatment facilities, even when funding has been assured from the outset. This should be factored into plans.

The number of ophthalmologists in training remains static[22] and as middle grade doctors retire they are very difficult to replace. Given recruitment difficulties in parts of Wales there is unlikely to be significant expansion in the ophthalmology workforce. Health boards need to consider how their services can be developed to fully utilise all available resources, including the introduction of non-medical injectors. There is a long lead-in period for the first group to go through training and activity will necessarily be reduced during this phase. The long-term benefits to the non-medical injector service are significant. Some thought should be given to the most effective way of deploying non-medical injectors. This depends on the clinic set up.

There has been an increase in the number of optometrists in training[23] and this sector of the eye care workforce will expand significantly in future. Many eye units in other areas of the UK make extensive use of hospital optometrists for service delivery. They typically work in the following clinics: macular degeneration treatment, diabetic retinopathy management, glaucoma monitoring, cataract assessment and emergency eye clinics.

[21] Clinical Council for Eye Health Commissioning: Community Ophthalmology Framework July 15.
[22] Health Education England: Proposed Education and Training Commissions for 2015/16.
[23] General Optical Council (GOC): Annual Performance Report 2016.

Traditionally, eye units in Wales have employed relatively few optometrists. This is a potential area for future workforce expansion.

We identified that cases of significant vision loss during treatment are probably under-reported in most units. Consideration should be given to streamlining the incident reporting process to encourage more reports.

Whilst our review highlights that progress has been made to improve services, these improvements have been inconsistent across Wales. Additional workforce planning is required to ensure that services are developed to maximise the available capacity to meet the growing demand for eye care services.

Following on from this review, HIW will be undertaking follow-up activity on recommendations made. This is to ensure that health boards are being vigilant in addressing these matters and taking all necessary action to improve the issues highlighted in our review.

Appendix A – Recommendations

As a result of the findings from our review, we have included the following overarching recommendations for health boards and policy makers to consider.

	Report finding	Recommendation info
1	Issues relating to patient referral process **(Patient Referrals – Referral Process)**	All parties (Welsh Government, NWIS, Ophthalmology Planned Care Board and Health Boards) must work together towards the introduction of electronic patient record/ referral system from optometrists directly to secondary care.
2	The CHC's National Ophthalmology Review highlighted that some patients felt they had not been provided with sufficient information regarding the reason for their referral. **(Patient Referrals – Referral Process)**	Health Boards via Local Eye Care Groups should work with optometrists to ensure that patients are provided with adequate and accessible information regarding the reason for their referral to secondary care and ensuring that all patients feel listened to and involved in decisions made around their care.
3	Quality of referrals being sent to rapid access pathway. **(Patient Referrals – Quality of Referrals)**	a) Health Boards should consider methods to refine referrals to ensure patients enter the most appropriate care pathway in a timely and efficient manner, avoiding unnecessary visits. b) Health Boards should consider providing educational events/material to raise awareness among optometrists and other relevant staff of local referral pathways. c) Health Boards should ensure feedback is provided to optometrists when required relating to quality of referrals sent to ensure learning.
4	Lack of feedback provided to optometrists following referral and discharge of patients. **(Patient Referrals – Communication Following referral)** **(Discharge patient – Quality of information)**	a) Health Boards should ensure feedback of diagnosis and a treatment plan is provided to referring optometrists following every referral made to the service, including whether a referral to a low vision service has been made. b) Optometrists must use the appropriate referral form and ensure that their name and practice address are clearly legible. c) Health boards/Welsh Government must ensure that systems are introduced to improve the amount of information available to optometrists in relation to patients who have been discharged from secondary care.

	Report finding	Recommendation info
5	CHC reports concerns around lack of information provided within secondary care prior to treatment. **(Patient Referrals – Communication Following referral)**	Health Boards must ensure that patients are provided with adequate information about their condition and proposed care plan prior to any investigation or treatment. This should conform to the principles outlined in GMC guidance on informed consent.
6	Concerns around set monitoring for follow-up patients. **(Treatment Timescale – Targets)**	a) The Welsh Government should ensure that Patient Administration Systems are capable of providing data on clinician recommended follow-up interval and actual follow-up interval by care pathway. b) Health Boards must ensure that care is provided for those (new or follow-up patients) with the greatest health need first, making most effective use of all skills and resources available. c) Clinical teams must clearly document the follow-up regime selected for each case. This should be applied consistently according to agreed protocols. The patient should be kept informed of any changes to the plan.
7	Lack of incident reporting relating to WG patient harm policy. **(Incident reporting)**	a) Health Boards must ensure that there are mechanisms in place to review incident reports to identify potential patterns providing early warnings to more serious system failures. b) Health Boards must ensure on the occasions where any incidents occur, inline with the WG policy related to patient harm, that these are reported as Serious Untoward Incidents (SUI's).

	Report finding	Recommendation info
8	Lack of capacity/Fragility of services of services due to over-reliance on consultants. Issues relating to lack of capacity, recruitment and lack of investment in services. **(Treatment – Capacity)**	a) Health Boards must proactively develop workforce plans which set out to address any shortfalls in the current service capacity and available facilities to mitigate the risks to patient care. These plans should seek to maximise capacity by making most effective use of the skills of medical and non-medical staff available, as well as available space/facilities. b) Health boards must consider ways to work more closely with colleagues from primary care. For example, providing equipment (and training) to optometry practices to allow them to undertake referral refinement and/or assessments on stable patients. This needs to be done in a planned and strategic way under control of the health board.
9	Health boards should learn from the experiences following progress made in other areas. **(Treatment – Initiatives to improve Capacity)**	a) Health Boards must ensure that they fully engage with the Ophthalmology Planned Care Board to aid shared learning from/ with staff in other areas. b) Welsh Government should consider whether there is a need to develop further approaches to encourage shared learning between health boards as well as more integrated methods to address common themes/issues being experienced across Wales. For example, the introduction of non-medical injectors.
10	Importance of the AMD Coordinator role. **(Service Support Staff – AMD Coordinators)**	Due to the demands of the role and the importance of providing continuity of cover, consideration should be given by Health Boards as to whether one AMD Coordinator is sufficient for the eye care service.
11	ECLO – lack of utilisation of the role from other staff. **(Service Support Staff – Eye Care Liaison Officer)**	Health Boards must ensure that all staff are aware of the availability of the local ECLO service. Ensuring patients have access to relevant advice and support.
12	ECLO – Limited capacity/cover. **(Service Support Staff – Eye Care Liaison Officer)**	Health Boards should ensure that there is ECLO for their eye care clinics at all times and consideration should be given as to whether one ECLO is sufficient for the eye care service.

	Report finding	Recommendation info
13	Concerns raised by staff in relation to a lack of processes in place to submit comments/ suggestions to health board management. **(Service Support Staff – Eye Care Liaison Officer**	Health Boards must ensure that there are methods in place to allow all staff to raise any concerns/suggestions about improvements to service provision they may have. This process should to ensure that feedback is routinely provided to individuals.
14	More clarity required in relation to evolving role of optometrist. **(The role of optometrist)**	To enable more effective utilisation of optometrists, Welsh Government must provide clarity to health boards relating to Indemnity, resource & finance arrangements, training/qualifications and communication mechanisms.
15	Additional utilisation of optometrists is required to increase capacity (HDHB example) and reduce the burden on secondary care. **(Utilisation of optomoterists)**	Health boards should consider additional utilisation of optometrists to increase available capacity and reduce burden on secondary care. Health Boards will need to ensure that issues are clarified around Indemnity, resource & finance arrangements, training and communication, for optometrists.
16	Patients not always being referred for their initial low vision assessment by secondary care staff. **(Utilisation of optometrists)**	Health Boards must ensure that staff are reminded of the importance of referring all eligible patients to an accredited optometrist for a low vision assessment.
17	Issues in relation to poor relationships between primary and secondary care staff impacting on progress to service developments. **(Primary and Secondary Care Relationship)**	Health boards must ensure that relevant staff engage with the local Eye Care Group. The group should meet regularly and be chaired by a member of the executive team. A key objective is to improve the working relationships between primary and secondary care staff to foster joint working initiatives.
18	Betsi Cadwaladr UHB did not have optometric advisor in post at time of our review. **(Primary and Secondary Care Relationship)**	Betsi Cadwaladr UHB must ensure that a permanent optometric advisor is recruited into post in line with the WG requirement.
19	Concerns raised about different criteria being used by different consultants, which subsequently means some patients are being followed up unnecessarily or treated with little chance of benefit. **(Discharging Patients – Criteria)**	Health Boards must ensure their AMD service has a policy setting out criteria for discharging 'wet' AMD patients in line with Royal College Guidance. The aim being to ensure that patients do not remain within the service longer than required. Maximising capacity for patients most likely to benefit. Adherence to the policy could form part of the annual service audit.

	Report finding	Recommendation info
20	Inadequate IT systems to capture useful date. Limited awareness of capacity and demand data. **(Information Management Systems – planning)**	Improvements must be made to information management systems within health boards to enable accurate capturing of capacity and demand (performance) data to allow for more informed workforce planning and to ensure resource provisions are based on patient need.
21	Issues in relation to information sharing. **(Information Management Systems – sharing information)**	Improvements must be made on improving the access to/sharing of patient information within health board areas to improve efficiency of services.
22	Lack of public awareness in relation to general eye care. **(Public Awareness)**	Welsh Government , Public Health Wales and Health Boards need to consider how the general public can be made more aware the importance of regular eye checks, general eye care issues, as well as the symptoms to look out for which are associated with the more serious eye conditions and the importance of seeking healthcare advice quickly. More information needs to be provided on the different services/professionals available to see/treat patients in relation to their eye care conditions.