

Acknowledgements

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Principal Investigators' Foreword

Providing care closer to home - the need for community based eye services

This report summarises our evaluation of four different pathfinder services for people with wet Age Related Macular Degeneration (wet AMD). They are provided in the community setting rather than the hospital. Based on our findings we make recommendations about the delivery and sustainability for the future of such community based services for people with wet AMD in Wales.

AMD is the leading cause of sight loss in Wales¹ and the UK and is one of the most **urgent** public health issues. The workload associated with wet AMD treatment is **growing rapidly** due to the ageing population and the regular long term follow up visits required by patients. Wet AMD is treated with injections directly into the eye. They have to be given at regular intervals and clinics struggle or fail to meet the recommended timings. Unfortunately, reports suggest that treatment times are often delayed by the increased demand for hospital eye services. The waiting times for treatment may result in further deterioration in the condition and sight.

A Welsh Government report states that in 2013-2014 approximately 15,000 treatments for wet AMD were provided at a cost of £16 million². The commitment to patients experiencing wet AMD results in a considerable workload for hospital eye services. Each person once diagnosed with wet AMD initially requires three injections at one monthly intervals and then, depending on which **anti**-vascular endothelial growth factor (anti-VEGF) drug is used, further injections at intervals of either 4 or 8 weeks, depending upon response to treatment and the anti-VEGF regime used. Wet AMD is a long-term chronic eye condition which may require treatment over many years.

Wales is not alone in facing the pressures of increasing demand and **insufficient capacity**. However, of the four UK nations, Wales has the highest percentage of people aged over 65 years and this is projected to increase by 36.6% between 2016 and 2041³. In light of the demographic pressures, **changes** need to be made to the way that wet AMD services are provided to ensure they are sustainable. The Welsh Government is committed **to modernising services** and providing **more care and support closer to home**⁴. This approach facilitates care in the community by investing in primary care and community based services normally provided by the hospital. In 2015 the Welsh Government made available £0.5m to fund four wet AMD pathfinder services in the community. It was considered important to capture and learn from

¹ <https://gov.wales/statistics-and-research/eye-care/?lang=en>

² <https://gov.wales/about/cabinet/cabinetstatements/previous-administration/2014/eyecare/?lang=en>

³ <https://gov.wales/statistics-and-research/national-population-projections/?lang=en>

⁴ https://gov.wales/topics/health/nhswales/plans/eye_plan/?lang=en

the pathfinder experiences and share what worked and learn from what did not work so well. To do that we were commissioned to conduct a service evaluation of the four pathfinder services.

In this report we present our findings and make seven high level recommendations about the delivery and sustainability of wet AMD services in the community.

1. **Putting people first:** listening, learning and responding to patients, their family, their carers and their needs.
2. **Co-production:** ensuring an inclusive approach to planning, development and service delivery and including staff who work and deliver the service, the patients, their families and carers and include third sector representation.
3. **Data gathering:** nurturing a culture of collecting and monitoring patients' outcomes as well as the health care activity needed to provide the service.
4. **Standardise practice:** building a culture of creating and using competencies, practices and procedures to reduce risk, increase staff confidence in their extending roles and improve the patient experience.
5. **Leadership of services:** Identifying a central person who negotiates effective 'working together' practices and seamless communications between services staff and patients.

In this report we evaluated three University Health Boards (UHB) and one teaching Health Board (tHB) pathfinder services. Each HB put forward a different model for provision of care for patients with wet AMD which reflected their local needs and resources. The implementation of the pathfinder services was not always as envisioned in the proposals, reflecting local issues and changing circumstances.

Elements of our recommended pathway can be seen in all of the participating pathfinder services as follows

- **Aneurin Bevan UHB:** Referral refinement service for suspected wet AMD patients by staff in a community optometric practice. Diagnosis is made by a consultant (via a virtual clinic) at the hospital. Patients are reviewed, treated and monitored in a community based Ophthalmic Diagnostic Treatment Centre (ODTC) staffed from the local hospital eye service which has a nurse led injection service.
- **Hywel Dda UHB.** Review and treatment of patients by hospital eye service staff in a community care resource centre with monitoring of 'stable' patients by optometrists in their community based practices.
- **Cwm Taf UHB:** Monitoring of 'stable' patients by hospital eye service optometrists in the community at a Health Park.
- **Powys Teaching tHB:** Review, treatment and monitoring of patients by trained community optometrists supported by hospital eye service medical staff in a community hospital.

Our evaluation was commissioned to assess the pathfinder services and to answer four main questions:

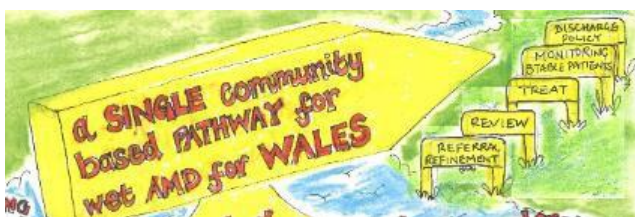
- How did the wet AMD services change?
- What was the impact upon clinical outcomes for patients?
- What were the stakeholders (patients, carers and staff) experiences/views of the change of service?
- What were the costs and consequences of the investment in the pathfinder services?

In this final report we have made seven high level recommendations to the Welsh Government. We acknowledge the challenges of austerity and demography and these are accommodated in our recommendations. Importantly the recommendations also prioritise the needs of the patients by improving their experiences and their visual outcomes. Implementing these changes should optimise the use of health care professionals and HB staff time within constrained budgets.

A description of the methodology and methods we used to undertake this evaluation are in Annex A.

High Level Recommendations

Recommendation 1: One pathway with five core elements



A standardised community pathway for Wales would include:

1. Referral Refinement;
2. Review;
3. Treat;
4. Monitoring of Patients Considered Stable;
5. Discharge policy.

We acknowledge that implementing all elements may not be suitable for all HBs. Some may choose to implement one or two of the elements depending on the additional capacity required, demography, geography, locations of the people in need and staff available.

Recommendation 2: Five principles of care for designing, developing and delivering a sustainable pathway



Underpin the community service pathway with five principles of care:

1. **Putting people first:** listening, learning and responding to patients, their family and their carers and their needs.
2. **Co-production:** ensuring an inclusive approach to planning, development and service delivery and include staff who work and deliver the service, the patients, their families and carers and include third sector representation.
3. **Data gathering:** nurturing a culture of collecting and monitoring patients' outcomes as well as the health care activity needed to provide the service.

4. **Standardise practice:** building a culture of creating and using competencies, practices and procedures to reduce risk, increase staff confidence in their extending roles and improve the patient experience.
5. **Leadership of services:** Identifying a central person who negotiates effective ‘working together’ practices and seamless communications between services staff and patients.

Recommendation 3: Harnessing the professional resources and talents to benefit patients



To expand capacity and reduce the pressure on ophthalmologists’ workload, non-medical health care professionals (e.g. optometrists, nurses, and orthoptists) should be trained to provide elements of the care pathway including injection treatments. Additionally the community optometric workforce can increase capacity. Community optometrists are ideally situated for patient convenience and for carrying out referral refinement and to monitor stable patients in their practices.

Recommendation 4: Nationally agreed competencies and training for non-medical Health Care Professionals



Standard procedures for wet AMD community based services should be developed through working together with patients, their family and staff. This will ensure that their needs and experiences are at the forefront of service planning, design and monitoring.

All medical and non-medical staff providing eye injections should be appropriately trained to provide the same



good quality service, so patients have confidence that they will receive a consistently good experience. Therefore, competencies required to undertake eye injections should be agreed nationally for all healthcare professionals. The injection service should have regular patient feedback, record adverse events and be audited with findings acted upon if necessary.



There are no specific competencies or training currently available in Wales or UK for roles and skills required for the elements of the new

recommended pathway. A working group should be set up to consider the training and assessment requirements.

Recommendation 5: Creating a person-centred appointment experience for people with wet AMD

Attention must be paid to ensure that HBs provide a



person-centred appointment system for follow up care. A reliable and person-centred appointment system leads patients to feel confident and results in them believing in the system. Many of the worries and frustrations experienced by patients regarding their appointments could be alleviated by the provision of the date of their next visit when they leave the clinic.

Recommendation 6: Embedding information technology and data collection into wet AMD pathways



Information technology should support services, inform patients of their care and enable

easy access to patient outcomes data. *Virtual clinics, integrated patient records, patient flexible*

appointment systems, collecting an agreed minimum data-set for patient management and determining outcomes of care should be incorporated within the new pathway.

Recommendation 7: Sustainable leadership for service delivery

Sustainable leadership where quality and delivery is maintained must be found within a



learning organisation. This includes the ability to transfer knowledge, motivate and empower others to lead when required, manage tension between the new shared vision of the pathway and the reality of practice.

Rationale for Recommendations

Here we provide the reasons for developing the high level recommendations including learning from what worked and what didn't work within the pathfinder wet AMD services.

The bibliography can be found in Annex B.

Recommendation 1: One pathway with five core elements

'you are part of the whole sort of business of it [...] you are treated as a person.'



Providing a wet AMD service is a complex management process for the HBs. Our evaluation of the pathfinder services led us to recommend a single community based service pathway for Wales combining the experiences of the pathfinder services. We acknowledge that implementing all elements may not be suitable for all HBs and some may choose to implement one or two of the elements depending on the additional capacity required, demography, geography, locations of the people in need and staff available.

Referral Refinement

Referral refinement was a key component of the Aneurin Bevan UHB pathfinder service. Patients are referred directly by their optometrist or GP with suspected wet AMD to a specially trained optometrist based in a community optometric practice. Patients are seen within two days for eye scans (OCT)⁵ and measurement of Visual Acuity (VA). The findings are then sent electronically for 'triaging' by ophthalmologists via a virtual clinic. Patients who the consultant deems to have

suspect wet AMD are then referred to the Rapid Access Clinic for confirmation of diagnosis and treatment.

What worked?

Referral refinement allowed those patients who have suspect wet AMD to be identified quickly and referred to the Rapid Access Clinic. The triaging of patients resulted in approximately a third of all the referrals (HB Report/data) referred for urgent assessment. The percentage of patients receiving treatment within the 14 days of referral substantially improved which reflects the fact that false positives are not being referred into secondary care, reducing the number of unnecessary hospital visits. The trained community optometrist also had the time to explain the condition and what would happen next, giving patients more certainty around their likely management.

What didn't work?

Only one pathfinder used community optometrists in this way, so in other HBs the hospital eye services continued to experience high level of referrals and false positives.

Review and treatment

After the patient is diagnosed they attend clinics where they are reviewed and treated. All the HBs implemented 'One stop clinics' in at least one location where patients are assessed and treated

⁵ OCT is a non-invasive imaging test that uses light waves to take cross-section pictures of your retina.

at the same visit. The premises used require a “clean room” where eye injections can be carried out and where an ophthalmologist or doctor is available on the premises if required.

What worked?

Using a clean room in a Community Hospital, Community Care Resource Centre and an ODTC by the pathfinder services (in principle) released theatre and clinic space in the HB hospital eye services.

Capacity was created by other health care professionals (HCPs) being upskilled to carry out various roles that would otherwise be undertaken by an ophthalmologist. Powys Teaching HB trained and utilised community optometrists to review patients and also gave the injections. Aneurin Bevan UHB already had a nurse led injection service before implementing the pathfinder service, which was able to move to the ODTC, whilst Hywel Dda UHB continued to use medical staff. The optometrists and nurses were primarily trained in house by the lead ophthalmologist in the service (See Recommendation 4).

The frequency of follow up appointments can be reduced by the choice of anti-VEGF drug and follow up treatment regime. All HBs used Lucentis and Eylea , except for one (which only used Lucentis). Aneurin Bevan UHB had officially introduced the “Treat and Extend” strategy for their patients being treated with Lucentis and the

other HBs were considering its implementation. By placing the clinics in the community setting travel distances were reduced by half for patients who were redirected to these Powys Teaching HB and Hywel Dda UHB pathfinder services.

What didn't work?

The capacity of the community based services where a non-medical injector was used was constrained by the requirement to have a trained doctor on site (not necessarily an ophthalmologist) to treat any adverse reaction. In Hywel Dda UHB the clinic was held in a resource centre with GP practices on site so a GP was only available during morning and afternoon sessions leaving a possible gap in cover around mid-day. However, a lack of non-medical staff who wished to train or were trained as injectors was another constraint on clinic capacity. Similarly in Aneurin Bevan UHB the ODTC and the Community Hospital in Powys Teaching HB could only operate on days when the consultant ophthalmologist was available to be at the clinic.

Monitoring of ‘stable’ patients

In Hywel Dda UHB optometrists in their community practices were trained by the consultant ophthalmologist to monitor patients who are considered to be “stable” according to the consultant’s review. The optometric practices were already equipped with the appropriate imaging machines (OCT) and optometrists were to carry out a clinical assessment (Visual acuity (VA), Slit lamp examination) and acquire OCT images to

enable them to make a decision as to whether the patient was still stable or need to be referred back for a second opinion or for treatment.

The optometrists in Cwm Taf hospital eye services added a session at Keir Hardie Health Park to their rotas to review patients considered stable and then discharge according to clear criteria. The optometrists, supported by a medical photographer and optical technician, worked in other hospital eye service clinics as part of a multidisciplinary team in secondary care. They were already trained to undertake clinical assessment by slit lamp examination and to review other clinical data collected by the team, (VA and OCT images) to make management decisions. Access to consultant support for the wet AMD pathfinder service is available, via a virtual clinic, if required which is a valued safety net for optometrists and patients.

A 'Monitor and Extend' regime for 'stable' patients was introduced that can reduce the number of visits required. If a patient is 'stable' and does not require an injection, their follow up period is extended by 2 weeks (4, 6, 8 weeks etc to a maximum of 12 weeks). If a patient remains stable for 12 months without injection, they are discharged back to their local optometrist.

What didn't work?

In Hywel Dda UHB the community based stable follow up service looked very promising initially, and embraced with considerable enthusiasm by

the community optometrists. The consultant was the critical link in the chain deciding who would be discharged to stable follow up by the community based optometrists. However when the consultant ophthalmologist went on long term sick leave the service was not continued as there were no protocols or standard operating procedures in place to decide who should be discharge to the community service (See Recommendation 3 and 4).

In Cwm Taf UHB the service had low take up which resulted in clinics working under capacity due to a low number of patients considered to be eligible who lived in the catchment area.

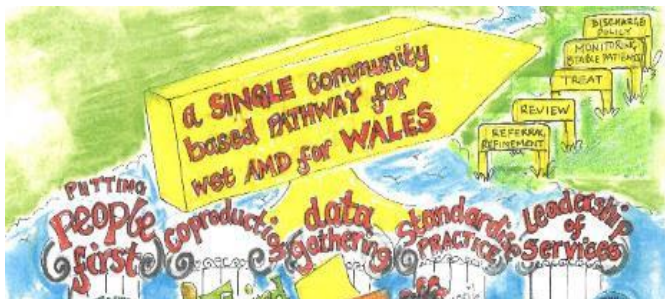
Different criteria for discharge appear to be used by different consultants in different HBs and some staff were unaware of the criteria.

Recommendation 2: Five principles of care for designing, developing and delivering a sustainable pathway

'I've asked the people there [clinic] questions and I've always had a good answer.'

'it makes all the difference, I've got a contact, there's a young lady called [name] who makes all the appointments [...] it's always good to have a contact, someone you can ring up if you're worried about anything.'

'right from the start, from the bottom level up, rather than the top level down, because it's much easier for people on the floor if they know that the service is going to be set up.'



The community service pathway should be underpinned by the following five principles of care:

1. **Putting people first:** listening, learning and responding to patients, their family and their carers and their needs.
2. **Co-production:** ensuring an inclusive approach to planning, development and service delivery and include staff who work and deliver the service, the

patients, their families and carers and include third sector representation.

3. **Data gathering:** nurturing a culture of collecting and monitoring patients' outcomes as well as the health care activity needed to provide the service.
4. **Standardise practice:** building a culture of creating and using competencies, practices and procedures to reduce risk, increase staff confidence and improve the patient experience.
5. **Leadership of services:** Identifying a central person who negotiates effective 'working together' practices and seamless communications between services staff and patients.

We based the five principles of care for community based wet AMD services on what patients, their carers and family voiced and also what the staff providing and supporting the services told us. Whilst much of what we heard was good, people were honest and told us what did not work for them but also gave us their views on what might work better.

What worked?

Patients, their families and staff valued clinics where there was a culture of listening, learning and responding to their needs. They interpreted this as a caring environment where they appreciated a certain standard of care. Information, counselling and treatment timeliness

enabled patients to make sense of what was happening to them, be able to consider the options available and understand how managing the long term condition would impact on their independence and daily life routines such as voluntary work, going on holiday and caring for family members. What helped this process was an identified key central person who carefully and consistently communicated the pathway vision, instilling confidence and resulting in patients feeling safe, more likely to accept the treatment regime; and they also earned great respect from fellow staff.

It was important to the patients in every pathfinder service that we understood that they would do anything to protect their sight and their independence. Initial diagnosis and sight loss which they described as a shock triggered anxiety which required each patient having to adapt their independent living arrangements to suite their variable needs. Patients and their families expressed mixed information needs which were often triggered by their own levels of inquisitiveness, resulting in them accessing information from multiple sources not just the clinic but from the internet, Macular Society and fellow patients. Therefore when patients and staff exchanged information about the process and disease this triggered a mutual appreciation which resulted in the patients valuing the relationships, having a positive experience and describing the staff as 'brilliant'.

What didn't work?

Where clinics were busy and there was insufficient individualised information, patients felt empathy, frustration, nervousness and worry, leading them to not wanting to ask questions which resulted in a perceived lack of individual information. They expressed worry at being 'lost in the system' or when they experienced a treatment delay they often explained the deterioration they experienced in visual welfare created a growing fear of loss of their normal activities and independence.

Where there were problems with clinic accessibility, overcrowding, parking and access to toilets, these generally originated from the early planning stage. The problems improved when patients and staff who worked in the clinics were involved in the process. Some issues were still unresolved at the end of the evaluation period. In one university health board a perceived lack of accessible patient toilets led to patients telling us that they had to ask for a staff escort to go through a private area to access the facilities.

Recommendation 3: Harnessing the professional resources and talents to benefit patients

'I think the best thing I think for us is the breaking down the boundary, I mean it's great working with [consultant], but now you know working alongside the other ophthalmologists and making them realise how good a job we are and how capable we are' [...]. They're not aware of what we are capable of doing, so maybe there's not the confidence to send them back into the community.'



To expand capacity and reduce the pressure on ophthalmologists' workload non-medical health care professionals (HCPs) (e.g. optometrists, nurses, orthoptists) can be trained to provide elements of the care pathway. In addition to clinic based care reviewing and treating patients as part of a multidisciplinary team, an increasing number of optometrists have the imaging equipment (OCT) in their practices that allows them to carry out a variety of tasks including referral refinement and the monitoring of 'stable' patients. There is a community of optometrists in Wales that has

demonstrated willingness to grow expertise and contribute more widely to patient care.

What worked?

In all the pathfinder services optometrists were upskilled and/or had their remit expanded to take a role in care that had been previously undertaken by a qualified ophthalmologist. The community optometrists responded to the opportunity with enthusiasm even at the expense of income to their community practices. The hospital eye service optometrists absorbed the extra wet AMD clinics at the Health Park with no impact on their other workload, seeing it as a natural extension of their other hospital eye service roles.

What didn't work?

Whilst engaged in treatment of patients the role of the optometrist has expanded considerably, the referral refinement role has not developed as fully. The current role of optometrist for referral refinement is data gathering, acquiring images and measure vision that is triaged by a consultant (on site or via a virtual clinic). However, trained optometrists could better employ their skills to carry out new patient triage.⁶ Different levels of decision making for non-medical HCPs are being developed from image acquisition with review by an ophthalmologist, to HCPs acquiring images and proposing a treatment plan confirmed by consultant and autonomous HCP clinic with access to consultant report if needed.

⁶ <https://www.rcophth.ac.uk/wp-content/uploads/2015/10/RCophth-The-Way-Forward-AMD-300117.pdf>

Recommendation 4: Nationally agreed competencies and training for non-medical health care professionals

'You know, like the first [injector] held my hand so tight [...] but um the last injection I had, [injector] kept saying to me all the time, "hold still, hold still, it's coming now". Well I worked myself up so much, I almost hyperventilated on the last one. But it was really bad. Oh my eye, I was in such a mess after that one. But the second injection, I didn't even have any redness, didn't have any bloodshot or anything. And but the third one, oh it was really bad for a week after.'

'There are no formal arrangements for sending people back in when, or discharging them and stuff, and it's OK when you've got [consultant] and you can send an e-mail and say, do you think we can send this, or this patient is like that [...]. But they, but just, just as a guidance thing, there does need to be a bare minimum of saying, you know, "this is when you can get rid of the patient out of discharge completely, this is when you need to send". You know, sending them back in is not something, are you happy, is it stable, well you're going to keep them.'

A recognised patient pathway with **protocols and standard operating procedures** (SOPs) ensures assurance and certainty of role responsibility and results in staff meeting and adhering to expected standards. **Formal training** for all staff within a new service takes time but is essential if it is going

to meet **professional/service standards** which is what patients expect. A step change approach to standardisation and service change builds staff and patient confidence which results in sustainability.



It is essential that patients have confidence that they will receive a consistently good experience of their eye injections. Both patients and their spouses reported some variable experiences of eye injections where staff had not completed training and competencies. Patients describe the injecting experience as something they 'dread' when awaiting the next appointment. It is important to note that patients reported that they **endured** their treatment regime because of their need **to save their sight**.

'I hate it, I honestly do hate it [...]. I don't like the injection in the eye, oh but I go [...]. I think to myself I got to try and protect my eye haven't I?'

'I don't like having them mind because they are not very nice at all but that is something you go to put up with', 'it's got to be done, it's better than going blind, you know. Because blindness is my greatest worry in life, you know if I went blind I think I would just shoot myself'. 'I just clenched my fists [...] it's an intrusion into your body [...] even after having 23 injections, I still tense up.'



Therefore all staff providing eye injections should be appropriately trained to provide the same good quality service

and competencies and training should be agreed nationally for all healthcare professionals. The injection service should have regular patient feedback, record adverse events and be audited with findings acted upon if necessary.

What worked?

Non-medical HCPs are involved in all elements of the pathway and their training has been primarily provided by the consultant ophthalmologists.

The need for Optometrists to practice independently in the pathfinder service in Cwm Taf UHB triggered the development of an unofficial training protocol with three key elements for the Optometrists to 'pass'. This resulted in them being 'declared independent and fit to start'. This is founded on a combination of optometrists' previous extensive experience and the training instilled trust resulting in the consultant gaining confidence in their practice.

Acknowledging risks also triggered the development of new service governance arrangements and resulted in identifying training needs.

The initial optometrists 'pilot' training with one

consultant in Hywel Dda UHB led to mutual trust with the outcome that standardised competencies and protocols were acknowledged as being required. Community optometrists and ophthalmologists working together alerted the need to share scan information to enable optometrists to review patients over time and provide better information.

The training provided for nurses and optometrists undertaking injections in the pathfinder service in Aneurin Bevan UHB and Powys tHB respectively was primarily carried out in house and led by the consultant ophthalmologist. All injectors were required to carry out 100 supervised injections before they were considered to be competent and could inject unsupervised. The origins of the exact number of supervised injections required to be competent could not be verified by the staff in our pathfinder services. This figure was set '*by the clinicians*', were '*just a number we choose*' and not evidenced by '*any published data*'. '*It's essentially what we have had from other units, from Moorfields, that their nurses have had similar number of injections. So who originally came up with the number, I don't know.*'

'We haven't got the formal, the sort of higher qualifications [...] and talking to people through it. And actually, having done, seen hundreds of these patients now, not all in the primary care, but so much of it is just experience, it's just looking at the patients, having the notes and doing the job. And I think that's really, you know, it's, I mean

[consultant] said on several occasions you know, we're the same quality, in terms of this particular piece of work, the same quality as mid grades.'

What didn't work?

Standard protocols were not in place in Hywel Dda even after investment in intensive training of the community based optometrists to provide the service, when the consultant went on sick leave the community based stable follow up service foundered.

Whilst care was taken to ensure the non-medical HCP injectors had a prolonged **training** supported by a consultant ophthalmologist, the medical injectors gave the patients a more variable experience. Some of the medical clinicians were locums.

'So he won't have him anymore. We, we have had him since, but fortunately that was the time when he didn't need the injection. And the receptionist told us if, if he needed an injection, I am to say that, could we arrange for an injection to be done in the following clinic.'

'And it, it is important from, from me or anybody else, to go in to have another [injection], because if the pain is not there, you'll go again. And again, and again. If you go in once and is, hurts you worse, you said, "well, I will never want to, want to go again". Well, that's bad.'

'We do have a training protocol that's not officially

been signed off yet, but that doesn't include competencies but it does include a fixed period of shadowing, I think it's two weeks that we've got down on there and then also one directly observed patient consultation with the consultant observing.'

Cardiff University provides an accredited Professional Certificate in Medical Retina course (duration 30 weeks) for eye care professionals which includes content on AMD. Of the 18 optometrists involved in the new services, eight have completed or are currently undertaking or are enrolled for the next course. This course covers a wide range of conditions, with nearly half of the content on diabetic retinopathy, and hence it is **not specific** for wet AMD. For non-medical HCPs in the community a more focused training programme, with agreed competencies for the skills required for AMD would be more appropriate.

It is now important that clinical competencies are agreed nationally for the different clinical roles undertaken by non-medical HCPs so that standardised training and qualifications can be provided. This will ensure that the work force will be developed to deliver safe and efficient care in the community.

It is recommended that a working group should be set up to consider the training and assessment requirements and how they could be implemented.

Recommendation 5: Creating person-centred appointment experience for people with wet AMD

'I know I have to have them [injections], so when that 8 weeks, then I go 9, 10, 11, that is the longest I have been is 11, I do start to get very anxious.'

'Now I was told [...] that the nurses were doing it, the lists were going to get shorter, and I would be having it every four to six weeks. But they haven't got any shorter, they've got longer. Now I've got it in the other eye [...] God knows what will happen [...] it's ridiculous.'

'He ends up having to phone to say you know I haven't had an appointment for a long time and it can go over twelve thirteen week period and of course he does then get concerned he knows he requires hospital eye services injections [...] and he will never turn one down, he will never say that's difficult.'

'I put up with it until I think, oh this is it, it's getting silly now, I'm having to move things around to see them, I can't see faces in the TV or anything like that, so that's when I phone up.'

For patient wellbeing it is very important that they are confident that patient appointments are scheduled at the correct time and that they are informed in good time. Late notification causes unnecessary anxiety and fear that they are lost in the system. This occurs where the monthly

booking system triggers appointments at short notice and with patients ringing to chase their appointments. This results in patient concerns about sight loss and sometimes inconvenience. The stress that is created by the uncertainty of when their next appointment will be is considerable and affects not just them but their families. Changes made to appointment times leads to patient and supporter frustration resulting in them not being able to plan life events and holidays.



A reliable and person-centred appointment system leads patients to feel confident and results in them

believing in the system. Many of the worries and frustrations experienced by patients regarding their appointments could be alleviated by the provision of the date of their next visit when they leave the clinic.

What worked?

Learning from this evaluation, investment in good clerical staff who care about the patient experience, understand the use of the available information technology and the routine software, the service and outcomes for patients pays dividends in terms of getting patients to their appointments and ensuring they know when their next appointment is to be. The staff are crucial

and are all part of delivering a valuable and valued service – information technology needs people to engage with it and the community of patients they serve.

What didn't work?

The culture of “...the computer says” or “... this is the system” is all too common and in three of the services patients could not walk out with their next appointment because the system did not ‘allow’ this.

Recommendation 6: Embedding supportive information technology and data collection into wet AMD pathways

'you used to before, they would give you a date for your next appointment where sometimes, you could say to them [...] you were going on holidays, or you had another appointment [...]. Well you could say to them "I can't do that day, could you do it another day?" [...] but today, they don't let you know until just over a week before.'

'it would be wonderful to have something given to us at the end of the session, "this is what has happened this time, there is no change. The prognosis is such at this time still". Then we can ask questions that are informed. At the moment, we've got nothing [...] it's often when I go home that I think oh why didn't I, but there you go!'

Information technology is all pervasive in NHS services. Care must be taken that it does not drive patient care and data access. In the interim period before the electronic patient record is rolled out a positive culture of data collection and utilisation needs to be established and rejection of a *"the computer says..."* culture. Rather information technology should support services, inform care and enable easy access to patient outcomes data. We suggest that by embedding the five principles of care into the information technology support to enable *virtual clinics, integrated patient records, appointment systems that facilitate on the spot 'next appointments' before the patient leaves the*

clinic, collecting a minimum data-set for patient management and determining outcomes of care.



All the pathfinder services collect/direct routine data from the patient (paper) record to various sources, all based on patient visits for treatment or monitoring and hospital IT systems (e.g. Merddyn). The hospital eye services systems link in with booking systems for appointments and other systems relating to services and diagnostic

tests. Some were better 'connected than others'. None of the hospital eye services routine data collections are intended for use in research.

Some of the pathfinder services set up additional data collections to be able to report back on the Welsh Government requirements and others had systems in place and data analysts assigned to undertake data extracts for this purpose.

The Electronic Medical Record (EMR) is planned for NHS Wales but whilst this may be necessary to improve communications and managing data it is possibly not sufficient. The HBs perhaps need to become more aware of the need to evaluation of treatment in terms of health outcomes (in this

case VA) as well as reporting activity.

This project has been an exemplar from the Welsh Government as it has emphasised that money invested in services has to be evaluated for the outcomes the investment has enabled. A culture of evaluation could be developed from this project by Welsh Government (every grant is accompanied by funding for evaluation) and in the health boards.

What worked?

All systems have a focus on capturing information regarding timing of appointments and the anti-VEGF injections as that is what is required by Welsh Government for regular reporting but also, importantly because the timing of injections is crucial for optimising treatment outcomes and preserving sight. All patient paper based records have the VA at the time of the visit recorded and most have VA included in supplementary electronic data collections.

Aneurin Bevan UHB had a clinician with a particular appreciation of the need to collect and analyse data on patients' treatment, outcomes and using the data to undertake informative analysis on (amongst other things) patients' visual outcomes. MS Excel was the software used – a software that is widespread and an excellent tool for data analysis. The reports the clinician has produced to share with Welsh Government and the HB are exemplary. However they are based on a data entered and managed by the consultant

independently of the routine data collection.

Powys Teaching UHB had a responsive and helpful team responsible for data management and had fairly complete data however some pertinent patient data remained with the service in Wye Valley NHS Trust.

What didn't work?

The evaluation was compromised by the lack of data to enable assessment of impact on patients and their visual outcomes. The prevailing culture related to valuing data, prioritising data collection for its use in feedback on how patients and the service can benefit from information based on their own data varied considerably.

It was clear that all the pathfinders had idiosyncratic systems and processes to capture data on top of the usual routine systems. Some had a focus for electronic data collection as a way to 'store' data in MS Excel or MS Access without an appreciation of how to set up data to enable analysis or reporting within these very flexible software tools. In one health board the recording of VA and entering the data at each visit into the local system of data capture had been started in one clinic but had met with some resistance in the clinic as it was thought to be too time consuming. In one HB the diagnosis and initial treatments were recorded in the hospital eye services at diagnosis but not linked to the data capture in the follow up services.

Recommendation 7: Sustainable leadership for service delivery

'But at the end of the day something has to make sure we develop this type of service right across really.'

'that's what's nice here [...] if we're short you'll see the consultants in there 'dropping' for us, you'll see the consultants in there helping us lay-up trolleys (agreement) [...] we're all mindful of each other.'



Sustainable leadership where quality and delivery is maintained must be found within a learning organisation. This includes the ability to transfer knowledge, motivate & empower others to lead when required, manage tension between the new shared vision of the pathway and the reality of practice. This is especially true through periods of transition when a process of change has to be managed with patients and their supporters gaining a sense of continuity of service quality, as happened within all of the pathfinder services. Drawing on our five principles of care this is where listening, learning and responding to people through a co-productive process and nurturing a culture of data collection and standardised practice can ensure that should a team lose a leader suddenly then the baton can be handed

safely to another person and services can be maintained to the same standard for patients.

What worked?

Empowered leadership committed to affecting the change, maintaining it, and further developing the service often led to a flat organisational structure within the new pathfinder services. In some services there was a sense of equality with clearly defined roles and sharing of knowledge within the multidisciplinary/ multiagency team. *'I love the team, the team have a great rapport [...] they are so willing to share their knowledge with me [...]. [Consultant] is so good, he has really got the time to sit down and explain things to you and I was included in the conversation.'*

Clearly defined roles in Brecon for example clinical lead, training lead, administrator (copied all notes into the database), optometrist injectors, support worker (patient reassurance), social connector (normalising daily life), coordinator/problem solver. This resulted in a flexible team who pulled together to fill the gaps when needed.

Every pathfinder service had made a considerable joint effort to *'make it work'* and the large amount of good will was evident throughout our conversations. Working together to get the job done was evident in the planning phase in some sites through multi-agency collaboration and also in the service delivery. So there was a shared expectation with regard to patient quality and some areas having 'rules of engagement'. Then

empowering team members to plan forward together to continuously improve, in accordance to changes that were needed *'there's a crisis in [name] and I'm trying to build a pathway between [consultant] and [consultant] [...] so another pathway to be considered. Because we've had one patient that got lost in the system and is no longer able to have treatment for wet AMD.'*

Staff motivation for establishing, being a part of, running and maintaining the new service originated from a sense of excitement of being part of it, they were attracted by success and desire to develop professionally. The prospect of obtaining a *'new skill'* sustained their interest and where they felt empowered staff felt more valued and recognised *'I've been allowed to step forward more and, whereas before people didn't perhaps realise or didn't see what we did in the department, they now see what we do.'*

Making sure that staff spent time with key people (*'theatre service guy, who sourced equipment'*) to ensure confidence in service delivery worked well in Powys tHB and in Aneurin Bevan UHB. For the sites where there were HCP in extended roles it included making arrangements for shadowing the consultant. In Cwm Taf UHB it included presenting cases to him and considering the percentages of agreement between them and providing a short OCT exam.

Co-locating a private organisation and a statutory organisation with multiple professionals triggered

some initial apprehension about working relationships and behaviours. These included changing mind-sets when developing the pathway *'the front-end of the pathway is Optometrists [...]* *"I need to refer this not to the hospital but to Specsavers Opticians" [...]* *that doesn't necessarily fit very easily with everybody '.* There was some concern about who would be coming to work in the building; and establishing accountability. However, initial reservations had subsided over time and the outcome was positive; *'they have been really great to work with, we love having them there. They are such a great bunch of people.'*

Exploring working conditions and relationships with staff in the first instance prior to the move to Friars walk resulted in a flexible mobile team who work in Friars Walk in Newport and also in Ystrad Mynach and Neville Hall in Abergavenny.

What didn't work?

There were some unresolved issues in some HBs such as transport and toilet accessibility, parking and extending times between appointments. It was apparent through our research that some attempt had been made to engage with statutory, third sector and patient groups to try and resolve them. However, what patients and their supporters told us was that these were real and important issues for them and in some of these issues they weren't being heard. These triggered feelings such as uncertainty, fear, anxiety, anger, guilt and disappointment in a group of people who

on the whole are very grateful for the treatment available and appreciated all the staff who they understood worked in very busy environments.

What is apparent from our research is that you can ask a patient and their supporters about satisfaction and you will likely get a response of between 90% and 100% of respondents who think the service is good or very good. However, it is important to listen to those people who are using and delivering the service to ensure that issues are identified and are resolved early in the planning stage and they are involved in changes planned later throughout the service pathway.

At the time of the evaluation the wet AMD service staff, particularly the ophthalmologists in one HB were going through a state of change with the lead consultant on long term sickness leave and the service having to use a number of locum staff. The initial 'pilot' training with the one consultant had led to mutual trust but this was not evidenced within standardised competencies and protocols. There were a number of consequences to this situation reported to us by patients, supporters and staff e.g. Patients' variable injecting experiences, increasing times between treatments, and the reduction in 'discharge' referrals to the community optometrists. Therefore our seven recommendations on the whole provide a collective approach to support the sustainable leadership role within the new pathway for wet AMD.

Conclusion

We gathered evidence from a wide range of sources to evaluate the four pathfinder services and make our seven recommendations. We would like to thank all those people who gave their time to participate.

What were the stakeholders' experiences of the change in service?

Based on our survey, generally 90-100% of stakeholders (patients, carers) thought the wet AMD services were *very good* to *good*. They appreciated all the staff who they understood worked in very busy environments. However, we have highlighted common aspects of patient experience that need improvement. These include the importance of information giving to the patients and carers on their condition, care and treatment schedule. This would include date and time of appointments, from initiation of treatment to the phased reduction, discontinuation of injections and monitoring of the wet AMD. This allays anxiety though knowledge of their condition and its management puts them back in control and ability to get on with their life with their family.

It is important that the agencies and the role of the third sector in support of clinical professionals is recognised and valued.

For some patients in one health board the perceived lack of patient accessible toilets and access issues for the ambulance service for some very frail patients were unresolved and were

expressed as challenging and at times embarrassing. The community service needs to be patients centred at all stages from planning, design, delivery and monitoring. These issues if addressed from the start do not need resourcing to any great degree, rather it is a matter of standing in the shoes of the stakeholders in the service and planning the service and systems with this perspective in mind.

How did the wet AMD services change and what were the costs and consequences?

In these new pathfinder services the changes in the service varied. Cwm Taf UHB invested in the equipment necessary to provide a service at a Health Park (Keir Hardie HP) but did not have to invest in more staff to provide the service there as there was only modest use of the service. However if the service were to scale up then there would be implications for staffing the service.

Powys tHB put together a financial plan based on the funding requested and received from Welsh Government which enabled the pathfinder service to be delivered on plan, on budget, to the benefit of the patients in terms of travel times, achieving targets for treatment times and over the year, saving the health board money. Community optometrists were keen to enhance their roles and train to undertake the injections and gained professionally from their participation. Whilst not pertinent to Wales *per se* the hospital eye services in Wye Valley NHS Trust benefited from the service as more capacity was created in their service.

In Aneurin Bevan HB there were no changes in staff resources and related costs used to establish the ODTC other than the initial investment in the equipment, setting up and renting the town centre facility. The main change in the new pathfinder service provided at the ODTC facility is the referral refinement step which alleviated pressure and increase efficiency in the rapid access clinic and ODTC. The limited availability of a medically qualified person in the ODTC restricts expansion.

Hywel Dda UHB were able to put a pathfinder service in place, but not as planned, nor with the extra staffing for which funding was available. In effect, the new service at Community Care Resource Centre (Crymych) had an opportunity cost as it drew staff from other locations in the HB to enable the service.

In two of the pathfinder services the travel distances were reduced by half, with many consequent benefits for the patients attending clinics for monitoring and treatment.

In Hywel Dda UHB Welsh Ambulance Service Trust (WAST) no longer transported patients who were transferred to the new Crymych service as this was not part of their contract. From the patient perspective, and the people who drive them to their appointments there was time saving and reduction in distance (approximately 50% of the journey length on average). The repatriation of wet AMD patients in Powys tHB patients to Brecon Community Hospital from Hereford hospital may

have reduced some use of WAST transport, however we understand that the majority of the patients were driven by relatives or used public transport. As with Hywel Dda UHB we had no access to transport data but from postcode analysis we know the journey length was reduced by approximately 50%.

What was the impact upon clinical outcomes for patients?

The changes made to the services to deliver the Pathfinder projects appear to have in all cases maintained or improved the vision outcomes for patients. Given the heterogeneity inherent in the data given the approach the evaluation had to take, it is nonetheless reassuring that if we informally benchmark the vision outcomes for Pathfinder Services with the outcomes reported by Liew et al in 2016⁷ the Pathfinder services are broadly similar.

Our evaluation of four pathfinders delivering wet AMD services in the community has shown that each pathfinder service has elements of good practice. We have drawn on these to propose ***one community service pathway for Wales with five core elements; referral refinement, review, treat, monitoring of patients considered stable and a clearly defined discharge policy.*** All these elements can increase capacity in services. It is designed on the principles of prudent health care using resources in the community, in particular optometrists in their community practices who have the necessary imaging equipment to allow

⁷<https://www.ncbi.nlm.nih.gov/pubmed/27419839>

virtual review by ophthalmologists. This is in line with The Cabinet Secretary for Health who states that ***“future service models need to ensure that we use the full skills of the eye care work force to ease the pressure on the hospital based services, making the best use of community optometry services to do this.”***⁸

The multidisciplinary approach of training and upskilling of nurses and optometrists to carry out tasks previously undertaken by ophthalmologists enables services to cope better with the increased pressures. Nurses and optometrists have been trained to provide injections. In addition, optometrists have been trained to undertake referral refinement (that speeds up diagnosis and treatment), assess and manage follow up patients and monitoring of stable patients. It is now important that nationally agreed core competencies are established for the delivery of intravitreal injections and the skills required by non-medical HCPs involved in the service delivery. Appropriate education, training and assessments for the skills need to be provided. Alongside this embedded in the services the creation of protocols and operating procedures in the hospital eye services and community services for wet AMD is critical to ensure continuity and high standards of care.

The importance of creating a positive culture around collection of health outcomes as well as healthcare activity data, together with intelligent

analysis and feedback into the service needs to be established. Creating this culture aids decision making, reduces risk and ensures that treatment is achieving its goals. There is an excellent example of this in one of the pathfinder services.

Harnessing the information technology resources in the HB and NHS Wales rather than being its servant will enhance the patient experience, patient outcomes and enable all the staff engaged in the eye services to deliver value based health care.

Funding will continue to be pressured due to the ageing population. The grants provided by the Welsh Government were effective in enabling the equipment and other capital investment to be made to improve the service. The services are currently sustainable at their current level but expansion may face funding challenges. The focus must now be in empowering HBs and their leaders to implement our seven recommendations and deliver a sustainable Wet AMD pathway with five core elements for Wales.

Many of our findings are in line with the Health Inspectorate Wales Ophthalmology Services Thematic Report 2015-16.⁹

⁸ WG Prioritised Eye Care Plan Actions to 2018
<https://gov.wales/docs/dhss/publications/170807eye-healthen.pdf>

⁹ <http://hiw.org.uk/docs/hiw/reports/170131opreviewen.pdf>

ANNEX A: Methodology

What we did

We used a range of research methods to do the evaluation. We asked the HBs for financial data, to find out how much the old and new services were costing, the numbers and amount of time used by health care professionals delivering the services and we also asked for data about the changes to the patients' vision before and after treatment to find out how well the new service was doing compared with the old services. We did not compare the pathfinder services with each other because the types and numbers of patients, the type of staff the HB had already and could potentially recruit varied. The geography and the location of services from patients' homes were also very different in each HB – each HB had unique circumstances which enabled different solutions to be tried out. However we did look for good practice that could be used in other HBs.

We also asked the HB service managers and finance staff, the health professionals providing the services and patients and carers to meet with our researchers to tell us about their experiences of the changes to the old services. The hospital eye services experiences were accessed through focus groups, semi-structured interviews and by filling in surveys.

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