Real patients coming to real harm

Ophthalmology services in Wales

Dr Tammy Boyce
Acknowledgements

I would like to express my gratitude to the clinical staff from health boards in Wales who were willing to share their experiences and insights into some of the capacity issues in the hospital eye service and the impact that this has on patients’ sight.

Our thanks also go to Dr Tammy Boyce, the Royal College of Ophthalmologists, Alex McMillan, Sian Biddyr, Elin Wyn and Andy Williams at RNIB Cymru for their input and support with producing this report.

Ceri Jackson
Director, RNIB Cymru

Cover photo: Andrew Bassett/Shutterstock.com
Contents

Why RNIB Cymru commissioned this report  4
Foreword 6
1. Introduction 8
2. Methodology 10
3. Findings 11
   3.1 Patients are going blind 11
   3.2 Waiting lists are long and the problems are getting worse 13
   3.3 Waiting lists are inaccurate 16
   3.4 The impact of long waiting lists for patients and the NHS 19
   3.5 Causes and solutions to capacity problems 21
      3.5.1 Unalterable causes and suggested solutions 21
      3.5.2 Alterable causes and possible solutions 24
4. Moving forward 32
References 34
Why RNIB Cymru commissioned this report

It’s a shocking reality that every day in Wales people are going blind unnecessarily because of capacity problems in eye clinics. Every week at RNIB Cymru we hear of patients experiencing significant delays for sight saving treatments and follow up appointments. Clinicians tell us that the system is breaking down and is unable to cope. This report by Dr Tammy Boyce highlights the impact of this and confirms that people are going blind in Wales due to cancelled or delayed appointments.

Staff have described the situation as “chaotic” and “outright dangerous” with patients waiting sometimes for years for a follow up appointment or even disappearing from the system altogether. Even when clinical staff offer suggestions for improvement they are often ignored. This frustration causes low morale with one consultant describing the situation as “crisis management on a daily basis”.

It is clear that there is a serious lack of capacity within the health boards to meet the increasing demand for ophthalmology services. We have an ageing population in Wales and the number of people with sight loss is predicted to double by 2050. This is compounded by an increase in some of the underlying causes of sight loss, such as diabetes and obesity. As well as planning for increased demand in the future the issues facing people today need to be addressed.

It is of grave concern that many health boards could not tell us how many patients are waiting to be seen. The bureaucratic systems that are in place mean that patients disappear into a black hole. RNIB Cymru wants to see new systems put in place to ensure eye clinics have the appropriate information to prioritise appointments in line with clinical need and not waiting time targets. It’s also of vital importance that patients are informed of the risks to their sight if their appointments are delayed or cancelled.

Another alarming finding in this report is the inconsistent approach to recording the incidence of patients losing their sight while waiting for an appointment. It is totally unacceptable that one health board medical director suggests that recording these on patient safety incident forms was “unhelpful”. This lack of data from health boards means that the report estimate of 48 people in Wales going blind because they are waiting too long for an appointment is a very conservative estimate.
RNIB Cymru is calling on the Welsh Government and health boards to take immediate steps to clear the backlog of patients waiting to be seen by ophthalmology services. In the longer term, a strategic plan needs to be implemented to ascertain and address the increasing capacity issues within ophthalmology services.

Nobody should lose their sight from a treatable eye condition simply because their eye clinic is too busy to provide care within a clinically appropriate timescale.
Foreword

The Royal College of Ophthalmologists acknowledges the issues highlighted in this report, and that these recurring themes are not unique to Wales alone but are prevalent across the UK.

A substantial part of the workload of ophthalmology services is the care of long term conditions such as glaucoma, diabetic retinopathy and age-related macular degeneration. These conditions all become increasingly common with advancing age and all require timely recognition and treatment in order to avoid preventable sight loss. Unfortunately, clinical services for these long term conditions seem to be particularly vulnerable and pressurised resulting in increased and repeated postponement of follow up appointments. Many hospitals have been artificially forced to have fixed new to review ratios such as 1:3 and are not paid beyond that. These arbitrary ratios are clearly incorrect for patients with chronic eye conditions who need regular lifelong follow up.

It is the view of the Royal College of Ophthalmologists that those responsible for commissioning and providing eye health services need to work together effectively to protect the eye health of the populations they serve. This is not to suggest that these problems are easy to solve, far from it. But we suggest that the first step towards solutions needs to be systematic ascertainment of eye health needs across health boards or clinical commissioning groups, followed by systematic capacity planning. In addition, we would go so far as to recommend that follow up patients are protected with a waiting time “target” just as new patients are and therefore provides them with equal priority.

For some aspects of ophthalmology, such as primary and emergency care, health need is inherently difficult to predict and the capacity of services is usually based on historical demand. However, this is not the case for the long term eye conditions, where incidence and prevalence are relatively stable and can be extrapolated to local populations from national statistics with a fair degree of accuracy.
To take glaucoma as a particular example, it is possible to predict with reasonable accuracy how many new appointments, follow up examinations, visual field tests and prescriptions for medication are likely to be required per annum at a health board level to ensure that all patients are seen by the right eye health care professional in the right location and at the clinically appropriate frequency. This process of capacity planning can then inform discussions about workforce planning and skill-mix.

Whilst not based on a robust study, the findings in the report highlight the pressing need for joint work to protect the eye health of the population and prevent avoidable sight loss.

Professor Caroline MacEwen
President, The Royal College of Ophthalmologists

The Royal College of Ophthalmologists
1. Introduction

We can save sight but the ability to do so is increasingly compromised. We have the tools and the staff but not the system. What’s going wrong?

In Wales, patients are going blind whilst waiting on lists. We conservatively estimate each year in Wales that 48 patients are losing their sight due to the length of time spent waiting to be seen in ophthalmology departments. This is because of a mismatch between demand and capacity – the number of ophthalmology patients is growing however the capacity to treat them is not.
Waiting lists are getting longer and the problem is worsening

Many patients are waiting longer than they should for review and follow up appointments – for example if ophthalmologists want to see the patient in three months, many patients are waiting six or more months. The length of time patients are waiting for their first appointments is increasing as well as the total number of patients waiting.

Patients that are waiting to be seen acutely (for example those with wet age-related macular degeneration (wet AMD)) are also waiting for too long.

Current waiting lists do not accurately reflect the true wait

Follow up patients, the majority seen in ophthalmology, are not accurately counted. We don’t know the full scope of the problem. In addition to patients irreversibly losing their sight, there are numerous direct and indirect effects of the long waits:

- increasing costs – due to falls, return visits to primary care
- increasing health inequalities
- reducing staff morale – clinics are overbooked, relationships with management are poor.

Reducing waiting lists must start now or the lists will get longer

- Develop and fund short and long term plans and targets set to reduce waiting lists.

Change referral to treatment (RTT) targets to emphasise follow up patients

- Collect relevant and accurate data to outline real demand. This may require modifying current IT systems and funding additional staff and equipment or infrastructures.
2. Methodology

The information in the report is based on findings from interviews and an RNIB Cymru survey.

In April 2014, 15 people in Wales were interviewed to gauge opinion on capacity in hospital eye clinics, this included: ten ophthalmologists, one nurse and two managers from six health boards. Two optometrists were also interviewed to supplement the information.

Some words have been added to the quotes in order to improve understanding, as they were taken from live interviews. However, the meanings have not been altered.

Eight interviewees were identified when they completed the RNIB Cymru survey in December 2013 and agreed to be interviewed for this research. The remaining seven interviewees were recommended by those interviewed (ie snowballing technique). The 2013 RNIB Cymru survey received answers from 11 ophthalmologists and four nurses. Respondents repeatedly stated all Welsh ophthalmology departments faced similarly dire capacity problems.

The aim of this report was to understand more about the capacity problems in secondary care in Welsh ophthalmology departments. The interviews with clinical staff utilised qualitative methods and generated rich data enabling this research to identify capacity problems in secondary care in Welsh ophthalmology departments. Representatives from six health boards were interviewed in order to provide an understanding of which issues were prevalent across the country. In the semi-structured interviews, interviewees were asked whether departments had capacity problems; to describe these problems, how they affected patients, how these problems arose, and possible solutions.

The World Health Organisation states “there are no rules for sample size in qualitative research” [1].

Of the 60 consultant ophthalmologists in Wales, ten were interviewed for this report, which equates to one-sixth of the workforce. Seven of the ten ophthalmologists interviewed were either previous or current heads of their departments. In addition to interviewing ophthalmologists, interviews were carried out with a small number of related staff that included optometrists, nurses and managers.

Data was analysed using a thematic analysis approach which allows meaning to emerge from the data [2].
3. Findings

3.1 Patients are going blind

Patients in Wales are spending so long on waiting lists that they are unnecessarily losing their sight. Ophthalmology departments do not have the capacity to meet the demand.

All ten consultant ophthalmologists interviewed from six health boards stated patients are unnecessarily losing their sight whilst on the waiting lists. This confirmed findings from the RNIB Cymru survey in December 2013 survey where over two-thirds of respondents (nine out of 14, with one abstention) said patients were either “sometimes or often” losing sight due to delayed diagnosis caused by capacity problems, or losing sight due to delays in treatment and monitoring caused by capacity problems. This is supported by survey findings in England where 37 per cent of 170 ophthalmologists and nurses said patients are “sometimes” losing their sight unnecessarily due to delayed treatment and monitoring caused by capacity problems. A further four per cent of respondents said this is happening “often”.

- “I think there’s little doubt, in aggregate, patients are coming to harm... in individual cases it’s hard to say if a patient would’ve got worse if he or she had been seen in a reasonable time scale. Were it not for that I think our Trust would’ve been sued to blazes, I think it’s only a matter of time before it does... I think there will be a scandal about this if they don’t do something.” Ophthalmologist with over ten years’ experience

- “Absolutely true...many could be losing their eyesight...we suddenly come across a patient who is progressing significantly whilst waiting for a clinic appointment.” Ophthalmologist

- “Several consultants have done clinical governance incident issues saying ‘we feel this patient has lost sight because of their delayed appointment’ because when they should’ve, say, been examined in two months’ time with possible need of more laser treatment, they haven’t received that treatment.” Nurse

There are inconsistencies in recording when patients are losing their sight whilst waiting. One health board in Wales completes patient safety incident forms as a result of patients permanently losing their sight whilst waiting to be seen. Another health board was discouraged from completing these
forms, their medical director advising it would be “unhelpful”. This confirms evidence from the Royal College of Ophthalmologists which found “under-reporting is widespread...only a minority of NHS incidents are reported.” [3]

Based on 2012 figures from the health board that does complete safety incident forms, we conservatively estimate each year in Wales that 48 patients come to “definite harm associated with delay in follow ups.” Based on their figure as a percentage of the Welsh population, we extrapolated to find that 48 patients are going blind each year due to the length of time spent waiting to be seen in ophthalmology departments.

Each year in Wales 48 patients are losing their sight due to long waits
3.2 Waiting lists are long and the problems are getting worse

“People need to...be assured they will have rapid access to services and support when they need it.” Mark Drakeford AM, Welsh Health Minister, September 2013

Despite the Health Minister’s commitment and increased support and the work by the Welsh Government and the Delivery Support Unit – ophthalmology patients in Wales are experiencing long delays for both new and follow up appointments. The number of patients waiting for their first ophthalmology appointment is increasing as well as the length of time they are waiting for the appointment.

Since 2012, waiting times for ophthalmology appointments have increased, particularly the number waiting over 36 weeks for their first appointment.

<table>
<thead>
<tr>
<th>More than 36 weeks</th>
<th>All Wales</th>
<th>ABM</th>
<th>AB</th>
<th>BC</th>
<th>Cardiff and Vale</th>
<th>Cwm Taf</th>
<th>Hywel Dda</th>
<th>Powys</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2012</td>
<td>809</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>111</td>
<td>692</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>January 2013</td>
<td>1059</td>
<td>2</td>
<td>35</td>
<td>512</td>
<td>285</td>
<td>216</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>January 2014</td>
<td>2468</td>
<td>51</td>
<td>198</td>
<td>1180</td>
<td>548</td>
<td>239</td>
<td>252</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 1. Patients waiting more than 36 weeks 2012–2014 (Welsh Government statistics)

Table 1 outlines the number of patients waiting more than 36 weeks for an ophthalmology appointment in January 2012, 2013 and 2014. Each health board in Wales was examined as well as the overall number of patients waiting in all of Wales. Overall in Wales the number of patients waiting more than 36 weeks for their first appointment has more than doubled between 2012 and 2014. In some health boards the increase is large – for example, Betsi Cadwaladr (BC) and Cardiff and Vale went from six in January 2012 to 1184 in January 2014. In some areas the increase is moderate (Aneurin Bevan (AB), Hywel Dda) and in the remaining areas there is no increase or a decrease (Abertawe Bro Morgannwg (ABM), Cwm Taf, Powys).
All interview and survey respondents agreed patients were not monitored or treated within clinically appropriate timescales.

Clinicians were more concerned that follow up appointments are frequently rescheduled or cancelled. Delays for these patients can lead to:

- “Real patients coming to real harm.”
- “Patients suffering irreversible visual loss.”

Interviews and surveys provided numerous examples of patients waiting longer than clinically advised – even for acute conditions like AMD. Ophthalmologists from two different health boards said the Royal College of Ophthalmology recommended timescale of a two week referral to treatment for wet AMD, is often not met:

- “We miserably fail to hit the two week referral. I don’t think we do more than 20 per cent in that time. The usual wait is a month to six weeks.” Ophthalmologist with over three years’ experience
- “AMD patients are waiting six to eight weeks.” Health care professional

Patients waiting under six weeks also waited longer than clinically advised:

- “We have a deficit of about 140 appointments every month for AMD alone...That’s the size of people we should be absolutely seeing in four weeks but we are not able to. Instead of seeing in four weeks, we see an average of every six weeks.” Ophthalmologist with over ten years’ experience

If ophthalmologists wish to book a patient more than six weeks later, they find patients disappear into a “follow up not booked system” or a “black hole”. This inability to book beyond six weeks (due to the Welsh Government’s partial booking policy which encourages healthcare providers to make appointments no more than six weeks in advance, the minimum period consultants have to give to take leave) is perversely harming patients, even those with acute conditions.

- “Sheer lack of capacity and follow up ‘not booked system’, implemented in a way which is outright dangerous and certainly led to people coming to irretrievable harm.” Ophthalmologist with over ten years’ experience
- “Some patients asked to come back in three months may come back nine or twelve months later and this is particularly a problem
with diabetic retinopathy where post-treatment you need to decide if more treatment is required and if the patient doesn’t pitch up for another nine months they can come to harm.” Ophthalmologist with over ten years’ experience

“Say somebody comes in with suspected glaucoma. I see that patient today and we say they need to come back in six weeks’ time and that never happens. And that patient completely disappears off the radar; they just go on the holding list. They don’t have the capacity to reappoint the patient and he just disappears. That happens in every health board...the patients wait and wait and wait.” Ophthalmologist with over ten years’ experience

“We have 2,000 patients on the holding list, patients who are attending once, waiting for further follow up appointments, who haven’t been given an appointment as yet because there is no capacity. The majority are glaucoma and diabetic patients and they are potential sight threatening conditions. Because they are on a holding list, nobody knows what the numbers are or what type of patient they are until they attend.” Ophthalmologist with over ten years’ experience

In May 2013, Betsi Cadwaladr University Health Board acknowledged that over 7,000 patients’ follow up appointment was more than 50 per cent overdue [4]. In interviews, consultants from different health boards also said ophthalmology patients in their areas were waiting years to be seen.

“I’ve seen glaucoma patients who are two to three years off their sell by date.” Ophthalmologist with over ten years’ experience

“Some patients on the holding list never get a chance to come into the system, they get pushed on and on. Some are waiting for two to three years - which is shocking.” Ophthalmologist with over ten years’ experience

Routine patients with conditions such as cataracts are “waiting and waiting and waiting” because ophthalmology departments only have the capacity to see urgent cases. Long waits on ophthalmology lists are becoming embedded in departments. One ophthalmologist examined their departmental waiting list and found 3.3 per cent of the entire Gwent population were due or overdue for follow up appointments in eye clinic. Long waits are also exacerbating health inequalities. In the old county of Gwent, Monmouthshire had high follow up rates compared to Blaenau Gwent and Torfaen with much lower follow up rates.
3.3 Waiting lists are inaccurate

Current waiting lists do not accurately reflect the true wait. Follow up patients, the majority seen in ophthalmology, are not accurately counted.

- “Follow up patients are never on the radar. They never come under the spotlight.” Ophthalmologist with over ten years’ experience

When asked if waiting lists were accurate for follow ups, all interviewees said they were either not at all accurate or not as accurate as lists for new patients.

- “Patients just disappear from the waiting list...mainly people with chronic conditions like glaucoma, diabetes...There was a patient last week who I saw in 2011 and wanted to see in three months. For reasons I don’t understand – they turned up as a new patient.” Ophthalmologist with over ten years’ experience

- “We found one list where patients could easily get lost. We have a main consultant list and have other eye lists, things like laser clinic or emergency eye clinic and we found some patients on those lists who are well past follow up dates but how they get into consultant clinics is not clear.” Ophthalmologist with over ten years’ experience

A National Audit Office report in 2014 found England’s official waiting statistics also do not capture the full waiting time experienced by patients from the time they are referred to treatment [5].

Because the waiting lists are so long, consultants are trying to circumvent the long waits but with little success.

- “If I see a patient I think ought to be seen in a year, I ask for an appointment in six months. If everybody does, it doesn’t help; it conceals the problem and makes it more muddy and complicated.” Ophthalmologist with over ten years’ experience

Another way consultants seek to reduce the waiting lists, particularly for acute conditions, is to overbook clinics. This practice leads to long waits in ophthalmology departments on the day of the patient’s appointment.

- “Overbooking is a big problem with us. Years ago you could say I’ve got so many slots left over in this clinic; we can fill them with new patients now. Unfortunately, because of targets and partial booking systems, all the slots are booked... urgent cases who are seen in clinic or casualty and need to come back within a week or two weeks’ time, are squeezed in as extras.” Health care professional
“Our clinics are about 50 per cent overbooked...if the patient needs to be seen in two weeks then I will see them.”
Ophthalmologist with over ten years' experience

In light of the rising number of patient safety incidents, in 2009 the National Patient Safety Agency recommended departments:

- review levels of hospital-initiated cancellation of appointments rates for patients with established or suspected glaucoma
- identify the number of patients currently awaiting follow up and confirm that there is sufficient capacity within the local health community to meet this number in terms of outpatient appointments and any specialist investigations [6].

Despite these recommendations and the increasing number of patients waiting longer periods, neither of these recommendations were implemented. In 2013 RNIB Cymru sent Freedom of Information requests to each health board concerning glaucoma waits. The requests included the following questions:

- For each month of the last twelve months, how many patients with glaucoma or suspect glaucoma or ocular hypertension in your health board area were not seen within 26 weeks of referral?
- How many patients in your health board area with a diagnosis of glaucoma have not been seen within their due follow up?
- How many glaucoma patients had appointments cancelled or rearranged?

The main finding of this Freedom of Information request was that data on follow up waits is not known as it is not collected. Only Cwm Taf Health Board answered. Five health boards namely, Abertawe Bro Morgannwg University, Aneurin Bevan University, Betsi Cadwaladr University, Cardiff and Vale University, and Powys Teaching stated they do not collect the data.

If one health board is able to collect this data, it can be expected that all health boards are capable of doing the same. That this data is not collected also affects and worries ophthalmologists:

- “The most dangerous thing is that there is no feedback to us. If I have a patient I want to see in three months and this is postponed, I’m not told, much less consulted.” Ophthalmologist with over ten years’ experience
In some areas, booking clerks decide which patients are cancelled or delayed. Interviewees agreed:

- “Booking clerks do not necessarily know the risk in that, in terms of the importance of the patient being seen in six or twelve months. The consultants and clinicians don’t make a decision about which patient is being pushed on.” — Health care professional

Follow up patients are never on the radar. They never come under the spotlight
3.4 The impact of long waiting lists for patients and the NHS

Ophthalmology departments are “heaving”. In the survey, 14 out of the 15 respondents said there was either “not enough capacity to meet current demand” or “lack of capacity is a significant problem”. Interviewees agreed clinics were “overwhelmed”.

Waiting increases costs
Long waiting times damage patients’ health and increase costs of care. “Waiting for treatment adds to health deterioration, increases financial costs to the NHS, and increases the burden on others, such as carers and general practices.” [7] Deteriorating sight loss is associated with falls and waiting increases the risk of falling. In 2009, estimates of the total cost of falls related to partial sightedness and blindness in the direct health care system (not including long term institutional care) was £25.1million [8].

Patients are going back to primary care for another referral
Ophthalmologists from three health boards stated patients are going back to their GP for re-referral.

▶ “It has reached such a stage now that patients are going back to GPs and GPs are re-referring them as new patients. They have a better chance of getting into the system as a new patient.” Ophthalmologist with over ten years’ experience

Health inequalities are exacerbated
Ophthalmologists said those patients who complained were more likely to be pushed up lists. Many described the “types” of patients unlikely to complain:

▶ “You don’t know about the ones who never are seen again. The ones we tend to recapture have the gumption to ring up and ask where’s my appointment gone? I suspect older women... who trust that the system is working as it should, are the ones who are losing out.” Ophthalmologist with over ten years’ experience

Staff morale is low
▶ “Morale is hugely down. We get blamed for lack of performance. We’ve met with our medical director. Constructive suggestions are given but it never gets implemented. It’s not the lack of solutions, it’s implementation of ideas...That is the irony, a lot of money is spent. Money is thrown in a very unproductive way.” Ophthalmologist with over ten years’ experience
“It is very chaotic; it’s always crisis management on a daily basis.” Ophthalmologist with over three years’ experience

“A lot of people are completely dragged down by the system ... some consultants are very good and others just have no interest at all, they’ve become inured to it all, they’re just dying for it all to go away.” Ophthalmologist with over ten years’ experience
3.5 Causes and solutions to capacity problems

“We’ve been making do and mending for several years.”
Ophthalmologist with over ten years’ experience

Interview and survey respondents named numerous causes of the capacity problems in ophthalmology departments.

3.5.1 Unalterable causes and suggested solutions

Increasing demand in services due to an ageing population

When the NHS was established in 1948 there were 200,000 people in the United Kingdom aged 85 or over. In 2014 this population has increased to 1.4 million and is expected to rise to almost three million by 2050 [9]. In addition, in Wales the population is older and consequently has increased health needs [10]. An ageing population places a greater demand on eyecare services as the prevalence of eye conditions increases significantly with age [11] [see Table 2].

Table 2 outlines the prevalence of the five most common sight threatening conditions in the UK and estimates their prevalence in 2010 and 2020. In all five conditions – wet AMD, dry AMD, glaucoma, early state diabetic retinopathy, diabetic maculopathy – the prevalence increases between 2010 and 2020.

<table>
<thead>
<tr>
<th>Sight condition</th>
<th>UK prevalence 2010</th>
<th>UK prevalence 2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wet AMD</td>
<td>415,000</td>
<td>516,000</td>
</tr>
<tr>
<td>Dry AMD</td>
<td>194,000</td>
<td>240,000</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>266,000</td>
<td>561,000</td>
</tr>
<tr>
<td>Early stage diabetic retinopathy</td>
<td>748,000</td>
<td>938,000</td>
</tr>
<tr>
<td>Diabetic maculopathy</td>
<td>188,000</td>
<td>236,000</td>
</tr>
</tbody>
</table>

Table 2. Prevalence of the common sight threatening conditions in the UK in 2010 and 2020 [12]
Increasing demand in services - more treatments available and developments in National Institute for Health and Care Excellence (NICE) guidance

All clinicians agreed that treatments and NICE guidance have increased the number of patients seen in ophthalmology departments. Whilst treatments for wet AMD reduced the number of people certified for visual impairment, ophthalmology departments were not allocated increased funding to administer these drugs nor for other new treatments or NICE guidance that increased their workloads.

“The new NICE treatments have created huge capacity gaps and we do not have adequate staffing to meet the demands of the service.” Ophthalmologist of over ten years’ experience

“NICE guidelines are fine, pharmacies get money back from the government, but I can’t implement the whole thing because I don’t have additional resources – that’s how the NHS falls apart.” Ophthalmologist with over ten years’ experience

In the future, waiting lists are likely to increase as health boards are yet to offer a number of NICE approved treatments due to current capacity problems:

“A lot of places do not provide to their local population things which are NICE approved...because of the capacity problems – doctors and space, staffing at all levels - nurse practitioners, orthoptists. (Interviewer: Have you asked for funding?) Yes, managers say they have no money.” Ophthalmologist with over ten years’ experience

Whilst the Welsh Government is unable to influence these two factors, there are other capacity related issues in Welsh ophthalmology departments that can be addressed.
3.5.2 Alterable causes and possible solutions

The policy emphasis on follow up patients

The current RTT targets emphasise the first contact or appointment yet the majority of ophthalmology outpatients are not new. Ophthalmology is outpatient based and patients tend to stay in systems. In 2011 and 2012, ophthalmology outpatient appointments accounted for 10.5 per cent of all outpatient appointments. The majority were follow up appointments – 244,965 versus 81,253 new appointments.

- “New patients are being seen to meet targets at the expense of follow up patients who have the risk of blinding disease, whereas the majority of new patients don’t. Clinical priorities have been skewed and people with potential blinding disease in need of follow up for diabetes and glaucoma and possibly treated tumours and AMD, these patients are in the backlog rather than the clinic.” Ophthalmologist with over ten years’ experience

- “All conditions, irrespective of whether they are disabling or not... are painted with the same brush... a skin tag... given the same weight as glaucoma, not acute conditions...” Ophthalmologist with over ten years’ experience

- “Last month some of my colleagues were breaching targets [13], cataract and squint patients were going to breach. I forfeited three of my theatre lists so that my colleague, who was struggling, could use my theatre sessions... but next month I was breaching. So it’s just shuffling them about.” Ophthalmologist with over three years’ experience

In 2011, the Royal College of Ophthalmologists warned that the emphasis on seeing new patients is “deeply flawed” and warned that “the consequences of these actions in term of irreversible loss of sight, may take years to manifest.” [14]

- “We’ve been arguing that there should be clinically oriented priorities rather than blindly following RTT. What hospital management is looking at is the pecking order. This patient is going to breach the RTT, we need to get them in.” Ophthalmologist with over ten years’ experience

Unless the Welsh Government changes the target, health boards will continue to chase the existing one – potentially leading to unnecessary irreversible sight loss. This is avoidable.
Shifting from short to longer term planning and targets
The emphasis on new patients has led to short term planning to meet the RTT targets with managers depending on solutions such as waiting list initiatives and delaying reappointing staff.

▶ “Robbing Peter to pay Paul. When vacancies come up they should be filled properly... if one nurse practitioner goes off you are left with a black hole.” Health care professional

Collecting appropriate data to identify and address the actual capacity problems in ophthalmology departments.
Basic information is not collected to address actual demands – such as who is waiting (glaucoma or diabetes patients), how many cataract patients are waiting, how long are patients waiting or how many appointments are cancelled?

▶ “The biggest issue for us is lack of outpatient diagnostic data. We are not in a position to say, without looking at notes, if a patient has glaucoma/diabetic retinopathy. We can’t plan.” Ophthalmologist with over ten years’ experience

▶ “How many patients have glaucoma? I honestly couldn’t tell you from the information we get back from Myrddin or clinical work station – it’s only by consultants physically going through every follow up patient can we get good information.” Ophthalmologist with over ten years’ experience

Managers and clinicians agree better evidence is needed to find the best solutions.

▶ “Rational decision making depends upon knowing how well services are performing. There are huge gaps in available data, and quite often the data that does emerge leaves clinical teams frustrated and suspicious. No one defends decision making in the dark, but this is precisely what follows.” [15]

IT systems, like Myrddin, should be modified to collect information useful in reducing waiting lists.

▶ “It’s not a good system... it’s not sufficiently detailed to breakdown the patients’ waiting - if you want to find who are the people who are really liable to come to harm.” Health care professional
Investing in IT
Evidence is growing that virtual clinics increase the number of patients seen.

“Every time I see a virtual patient in three minutes I’m freeing up 17 minutes of doctor time.” Ophthalmologist with over ten years’ experience

Scotland has funded improved IT links between hospitals and optometrists and reduced waiting lists. In 2011 the Scottish Government funded a £6.6million IT link so High Street optometrists would have a secure digital connection to eye clinics in hospitals - allowing them to transfer digital images instantaneously, removing the need for a referral pathway through GPs. This resulted in a considerable reduction in waiting times and freeing up secondary care [16].

Investing in IT will enable waiting lists to be properly validated. Departments in five health boards attempted to validate waiting lists. All validation exercises resulted in reduced waiting lists. Consultants in one hospital who validated their follow up lists estimate that about five to ten per cent of patients are at a particularly high risk of harm.

“Many patients are still on the list who shouldn’t be. We have gone through some of them and validating reduced 20-30 per cent of the original list. We are not validating now – because it requires time.” Ophthalmologist with over ten years’ experience

“We have validated in an ad hoc way for some time. Since December/January 2014 I’ve been doing it systematically. I did it with 1200 patients who were delayed follow ups on my list and locum lists. Found about 20 per cent suitable for nurse led clinics, around 40 per cent patients didn’t need to be followed up at all... it was skewed a bit because of a locum and he tended to bring people back that perhaps we wouldn’t.” Ophthalmologist with over ten years’ experience
Annual or consistent validation of waiting lists is a potentially sustainable way to reduce waiting lists.

North Wales’ efforts to reduce waiting lists

Consultants in North Wales sought to reduce lengthy waiting lists in two ways. These include:

a. Prioritising

The project had mixed results. Referral patients (from GPs and optometrists) were categorised as:

- P1 – conditions where a delay will produce irreversible harm to patient (for example glaucoma, diabetic macular oedema)
- P2 – reversible harm (for example cataracts)
- P3 – no harm produced as a result of deferred or delayed treatment apart from inconvenience (for example watery eye or skin tag).

Prioritisation was carried out in three areas initially but is now only done in Central areas because IT systems are unable to capture the necessary data in Wrexham and Bangor – where the pilot stopped in 2013. In the Central area, prioritising demonstrated a significant improvement. However, even in the Central area disadvantages arose. Clinically important patients were seen sooner but few of the cataracts were seen (as they come under P2) and some P3 patients were never seen.

b. Optometrists

Optometrists reviewed notes to identify “long waiters” – patients waiting more than 50 per cent over the follow up date (for example patient waiting to be seen in six months now waiting over nine months). Again, this effort to reduce the waiting list had mixed results. In Bangor a selection of patients were analysed and all children, and patients with glaucoma or diabetic retinopathy were removed.

In Wrexham a random sample of patients were analysed. The success of this project requires better analysis. There is no doubt that the number of patients on waiting lists reduced but interviewees claimed a reduction of between five to 60 per cent - depending on the method used. Efforts to reduce lists, such as this, are not analysed or publicised and this greatly misses an opportunity to efficiently reduce waiting lists across Wales. It is efficient and more sustainable for the Welsh Government and health boards to share information about their own efforts to reduce waiting lists.
Waiting lists will not decrease without more staff

Despite the increase in treatments, numbers of staff in ophthalmology departments are decreasing. For years the number of ophthalmic staff increased but these numbers are now moving in the opposite direction.

At 31 December 2013, there were 781 ophthalmic practitioners on health board lists, a decrease of 28 (3.5 per cent) on the previous year and an increase of 152 (24.2 per cent) since 2003. 773 (99 per cent) were optometrists (a decrease of 22 from 2012) and eight (one per cent) were ophthalmic medical practitioners (OMPs). Since 2003 the number of optometrists have increased by 179 (30.1 per cent) and OMPs have fallen by 27 (77.1 per cent) [17].

In North Wales consultants at Wrexham Maelor hospital see over twice the number of new patients as the other two hospitals [Table 3]. Whilst the shortfall in staff has been highlighted to the Welsh Government, Wales Audit Office and the Royal College of Ophthalmologists, the department has been told repeatedly “there’s no money for additional consultants”.

Table 3 outlines the number of new patients seen by consultants in North Wales. It shows that consultants at Wrexham Maelor hospital see many more new patients compared to the other two hospitals in North Wales, suggesting a shortage in staff at Wrexham.

<table>
<thead>
<tr>
<th>Area</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wrexham</td>
<td>2,024</td>
</tr>
<tr>
<td>Central</td>
<td>1,007</td>
</tr>
<tr>
<td>Bangor</td>
<td>908</td>
</tr>
</tbody>
</table>

Table 3. New patients seen by consultant – North Wales

Staffing solutions do not mean hiring more doctors, but it does mean spending some money.

“The main areas where the demand is much greater than capacity is glaucoma and medical retina...We’d like to set up nurse led glaucoma clinics, virtual clinics. We could use up to four more nurse practitioners (Interviewer: Have you asked for funding?) Oh yes, they say they haven’t got any money.” Ophthalmologist with over ten years’ experience
“If you want to save money by using a band five person to see a glaucoma or AMD patient rather than a consultant to see them, you have to spend a little bit of money upgrading that person. In the long run you do save money but health boards haven’t got any money at all. To innovate they have to spend.” Ophthalmologist with over ten years’ experience

Some consultant ophthalmologists “need to learn to trust their colleagues in allied professions” (RNIB Cymru 2013 survey findings) but many stated they understood that clinical nurse specialists, orthoptists and technicians have an increasing role in reducing waiting lists.

“I don’t care who does the work… the majority of the consultant body in ophthalmology is aware that the only way we’re going to get this work done is by all hands to the pump, the appropriate hands and, if you want to look at it from a manager's point of view, the cheapest hands that can do any particular part of the job.” Ophthalmologist with over ten years’ experience

“We need to replicate the glaucoma nurse practitioner system for the AMD clinics and increase the hours of these sorts of people… because nurse practitioners are very good in these roles but they don’t grow on trees.” Ophthalmologist with over ten years’ experience

Addressing problems related to department infrastructure. If staffing issues are addressed, infrastructures will also need to be considered in order to meet actual capacity. Consultants from five health boards identified a number of related issues and solutions:

“We have eleven consultants in a department designed for four. We have a new hospital… have expanded our footprint but we’re still really at limit of our space in service like Lucentis or wet AMD treatment.” Ophthalmologist with over ten years’ experience

“We have a bay for eye patients and if there is a big winter pressure, lots of patients with flu, they take over our eye bay and eye lists get cancelled. Last year we lost about six to eight weeks in two months... 60-70 appointments a week.” Ophthalmologist with over ten years’ experience
“We’ve made it clear that there is availability during the week... We’re not using our time as efficiently as we could during the week. There’s also staffing levels to consider, if I’m free and theatre’s free that’s great, but it doesn’t work that way. I need nurses and others.” Ophthalmologist with over ten years’ experience

“We need seats in the waiting area.” RNIB Cymru survey findings

“We keep telling them they are wasting money on waiting list initiatives. It’s not a sustainable solution... our Monday to Friday capacity is not fully utilised because of various reasons and come to the weekend, they throw a whole load of money to see these patients again on Saturday and Sunday and it’s absolutely barmy! It’s scandalous, it’s tax payers money... we’ve said our space utilisation is poor, we’ve showed them the figures and why it is happening... we’ve said we’re not doing any weekend work until we get a sustainable solution.” Ophthalmologist with over three years’ experience

One way to fund improvements to departments is to use the Lucentis funding in ophthalmology departments instead of redirecting it out of the department. Ophthalmology departments receive £1,350 per assessment for patients receiving Lucentis wet AMD injection treatments and £65 per visit for assessments without injections. Ophthalmology departments should benefit from their own work.

“They’ve diverted all of the millions of pounds of Welsh Government subsidy for other purposes. It’s been difficult to get the infrastructure for the Lucentis work. They’ve refused to spend any of it on equipment or anything like. Welsh Government bought us an OCT (Optical Coherence Tomography) machine even though getting subsidies per patient.” Ophthalmologist of over three years’ experience

“My health board has been embezzling the Welsh Government subsidy and spending it on other things.” Ophthalmologist with over ten years’ experience
4. Moving forward

The Welsh Government needs to fulfil its commitment to:

• revise targets for ophthalmology to incorporate measures for all patients (new and follow up) that are based on clinical need and risk of irreversible sight loss

• work with health boards to develop systems to improve routine data collection for demand, capacity, activity and backlog.

In order to meet these commitments the Welsh Government should:

• understand and plan to match demand against actual capacity

• create targets longer than one year:
  • to reduce likelihood of perverse incentives that cause departments to chase targets rather than address underlying problems

• public reporting to be service and condition specific

• invest in IT, it is a solution – not an afterthought or the first budget cut:
  • virtual clinics save clinician time and increase the number of patients seen
  • roll out the Open Eyes electronic patient records system across Wales. With Open Eyes clinicians are able to access all the information they need about their patient in one place.

Together we can reduce waiting lists
In 2014 the Welsh Government can also:

- improve patient communication. Patients have a right to expect timely and good information on the length of waits – particularly what to do if appointments go beyond the time requested by clinicians

  “The real mischief of the system is it is completely opaque to patients and to us. If you are trying to find out when you are going to be seen, you can’t.” Ophthalmologist of over ten year’s experience

- address staffing capacity issues – see the whole ophthalmology team as the solution
  - in Scotland the use of optometry and effective triaging in primary care reduced hospital referrals by 25 per cent
  - solutions are not just staffing costs – nurse practitioners require adequate space to see patients

- fully implement all eyecare pathways across Wales

- better understand and share results of efforts to reduce waiting lists

- commit to increased funding:
  - prevention is not cheap or free. The Welsh Government should plan and fund both prevention and treatment. Waiting lists will not decrease without investment. Ophthalmology departments are working at full capacity. You cannot expect more.

In 2015–2020 the Welsh Government can:

- plan targets for follow up and new patients

- reduce waiting lists

- create IT systems adequately analysing capacity problems, able to identify waiting list issues

- address staffing and spacing issues in ophthalmology departments to reduce waiting lists.
References


12. RNIB (2013) Saving money losing sight. RNIB.

13. Cataract targets in Wales: “No-one to wait more than 4 months for cataract treatment”. bit.ly/102qeFP


16. Hi-tech scheme for serious eye problems [bit.ly/1tZfvcB]

I think there will be a scandal about this if they don’t do something

Ophthalmologist with over ten years’ experience