



Don't lose sight! Don't delay!

Perspectives on the wet age-related macular degeneration (wet AMD) patient journey

RNIB campaign report



supporting blind and
partially sighted people

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Clara Eaglen, Policy and Campaigns Manager, RNIB
Steve Winyard, Head of Policy and Campaigns, RNIB

About RNIB

Royal National Institute of Blind People (RNIB) is the leading charity offering information, support and advice to almost two million people with sight loss.

We are a membership organisation with over 10,000 members who are blind, partially sighted or the friends and family of people with sight loss.

Our three main priorities are set out by our five year strategy (2009–2014):

- stopping people losing their sight unnecessarily
- supporting independent living
- creating an inclusive society.

As a campaigning organisation, we fight for the rights of blind and partially sighted people across the UK and push for better access to diagnosis and treatment to prevent avoidable sight loss.

1. Executive summary

Introduction

Over the past decade there has been a revolution in the treatment of age-related macular degeneration (AMD). In the early 2000s a diagnosis of AMD by an ophthalmologist was invariably accompanied by the words, "I'm sorry but there's nothing more I can do." Today things are very different. Effective treatment via intravitreal injections is available and the number of people certified as blind or partially sighted due to wet AMD is falling.

This is enormously welcome. Nevertheless, wet AMD is still one of the biggest cause of sight loss in the UK and demand for services is rising with the ageing population. Why then are people still losing their sight due to a treatable condition such as wet AMD?

In autumn 2012, to try to answer this question, RNIB commissioned a major piece of research to look at the issues from the perspective of patients, carers, clinicians, commissioners and other health care professionals. For the first time, by talking to all the key players, we hoped to identify the main problems within the current system and possible solutions to them.

Methodology

The research was based on in-depth telephone interviews conducted by an external agency, The Campaign Company. Interviews were carried out with a total of 95 patients and a further 68 carers, clinicians, commissioners, and other professionals working in the health environment, predominantly in England. The interview scripts were detailed and combined a series of open and closed questions covering amongst other things awareness, care up to diagnosis, treatment and additional support. The detailed nature of the questions meant that few interviewees answered every question but by analysing all interviews and the literature, a full picture of care emerged.

Key findings

Why are patients still losing their sight due to wet AMD? Our research suggests six main reasons.

Patients' lack of awareness of the signs and symptoms: far too many people are unaware of wet AMD and its symptoms. Many patients delayed seeing either their optometrist or GP, unaware of the need for urgency. Almost two thirds of the patients interviewed said they were unaware of wet AMD prior to diagnosis and that they could lose their sight within three months from it. In many cases, by the time they had reached a retinal specialist and been treated, a significant amount of vision had been

lost. There was also little understanding that there are two types of the condition that impact on the macula in different ways and have very different prognoses. Patients interviewed said that very little is done by the NHS to explain the differences between the two types; while some clinicians and commissioners felt that communication about wet AMD posed challenges because of the terminology of the condition.

Patients' lack of awareness of the treatment pathway: there is a clear mismatch between patient expectations on speed of diagnosis and treatment and the actual guideline recommendations. The majority of patients interviewed, whose diagnosis took much longer than the recommended timeframe, described it as either "quite fast" or "very fast". Patients also reported being far less informed about what is going on in the diagnosis phase than once they are receiving treatment. This lack of knowledge meant that some patients did not act rapidly and seek professional help as soon as they noticed a change in their vision.

Delayed diagnosis and ineffective referral pathways: the Royal College of Ophthalmologists recommends no more than seven days between first contact with a health professional (usually either the optometrist or the GP) and receiving a diagnosis from a retinal specialist. However, less than one third (31 per cent) of patients achieved this. The research indicates a number of reasons for this. Prominent amongst these is a lack of awareness of rapid referral procedures for wet AMD amongst some optometrists and GPs. This may be due to different procedures being used in different parts of the country and new staff or locums not being informed of the local procedures. Another important reason for delayed diagnosis is inefficient referral pathways. In some parts of the country, optometrists are required to refer wet AMD patients to the eye clinic via their GP and this can introduce significant delays.

Insufficient capacity in eye clinics: the fourth reason why many people are still losing their sight due to wet AMD is insufficient capacity within the system. A variety of factors were mentioned in the research – too few retinal specialists, nurses and support staff; insufficient clinic space and not enough specialist equipment (e.g. such as Ocular Coherence Tomography (OCT)). Contributing to this problem is the over-referral of wet AMD suspects by primary care professionals to retinal clinics. Clinicians did highlight that it would be wrong for them not to refer potential cases and that providing access to tools, such as OCT, in the community could increase the accuracy of identifying potential wet AMD patients.

As a result of inadequate capacity the intervals between patients being seen (and if necessary re-treated) are growing in many centres. What should be a monthly check can extend out to six or eight weeks and in a few cases longer. Clinicians reported that greater priority is often given to the initial first three injections in wet AMD treatment in order to meet referral to treatment targets.

The slippage in treatment after these three injections affects patient outcomes as, if left untreated, wet AMD develops rapidly over days and weeks and causes permanent sight loss.

Insufficient support during the patient journey: for patients losing their central vision, the emotional toll can be enormous. Some patients reported feeling depressed, anxious and emotionally distraught. However, there is insufficient support to assist people during their wet AMD journey. Information and emotional support at time of diagnosis can be vital and this should be available through an Eye Clinic Liaison Officer (ECLO) or equivalent. However, all too often it just isn't there. Similarly, many patients who have experienced some sight loss need support through low vision services yet can wait six months or longer for this. Also the quality of the low vision and rehabilitation services that are provided varies greatly across the country as does the funding for these services.

Weaknesses in commissioning: there is a widely held view amongst both commissioners and clinicians that commissioning of wet AMD services could be done much better. This is partly due to a simple "lack of capacity to commission". Most of the 32 commissioners we surveyed cover a broad range of services such as "all of acute care". Retinal care is only a very small part of their work, with wet AMD an even smaller subset. Many feel over-stretched and find it very hard to keep up with the latest developments and best practice. Many also feel there is insufficient information on which to base informed judgements. In fact, over half said their commissioning board did not receive regular reports on the performance of eye care services or information about eye health issues. Patient feedback also plays a limited role in informing commissioning decisions.

Recommendations

It is vital that these issues are tackled. Thousands of people are losing sight unnecessarily due to wet AMD and without urgent action this number will only grow.

- 1. Early presentation:** critical to ensuring that patients with wet AMD go to see their optometrist or GP earlier is improved awareness of the disease amongst the public. Close to two thirds of patients interviewed for this report were not aware of wet AMD when first diagnosed. There is a need for sustained awareness of wet AMD. Patient support groups are ideally placed to contribute to awareness raising. Optometrists and GPs should also make “every contact count” by educating at-risk patients about the need to seek rapid professional help if they notice changes to their vision. Patients must check the vision of each eye to ensure that one does not compensate for the other and mask initial signs and symptoms of wet AMD.
- 2. Empowering patients:** from the moment a patient is suspected of having wet AMD they should be made aware of the need to act rapidly. Primary care professionals should stress the need to be seen by a retinal specialist within seven days, without the need to go into detail about the possible diagnosis. Once diagnosed, secondary care professionals should outline the treatment pathway and its timeframe. By making patients aware of the time a diagnosis should take as well as the treatment pathway there is a much better chance they will act if the system fails them.
- 3. Rapid diagnosis:** to ensure much speedier diagnosis and treatment, there needs to be greater awareness of fast track referral processes so that patients are quickly directed to a retinal clinic for diagnosis and treatment. Staff meetings in opticians and GP practices should be used to inform and refresh all team members about the signs and symptoms of wet AMD, the need to act rapidly, and what rapid referral procedures are in place locally. New staff, including locums, must be informed about local referral processes as part of their induction training. Commissioners should take the lead in ensuring local referral pathways for wet AMD are designed to direct suspected wet AMD patients to the retinal clinic as quickly as possible. In fact, as rapid referral procedures vary so much across the country, there is a case for developing a national rapid referral scheme to ensure all wet AMD patients have equal access to rapid diagnosis and treatment.
- 4. Increased capacity and innovation:** hospital eye departments across the country are struggling to provide a good service for their patients, whether they have wet AMD, glaucoma, cataracts, diabetic retinopathy or other less common eye conditions. The system is already under huge pressure and with increasing demand due to an ageing population and new NICE approved treatments this will only increase. There is an urgent need for more resource. Despite the extremely tight public expenditure environment the case for increased spending on eye care services still needs to be made.

Whether eye care gets the additional resources it so urgently needs or not, there is considerable scope to innovate and provide treatments in more cost effective ways. There is strong agreement that more could be done outside of the eye hospital with commissioner funded OCT equipment in the community. If OCT scanners are not only placed in key areas in the community but electronically linked to ophthalmologists in clinics this can reduce unnecessary referrals for diagnosis, preventing bottlenecks in the pre-treatment phase. This approach can also be used during the treatment phase to establish whether a patient needs to go to hospital for an injection.

Our research also highlighted innovation in the areas of staffing and service design. In some hospitals nurses and optometrists are taking on expanded, specialist roles such as running clinics for patients whose condition has stabilised. In a few areas of the country, nurses are now carrying out the intravitreal injections under the supervision of ophthalmologists. There are clear advantages to using the multidisciplinary team in service provision as this will free up ophthalmologists' time and enable them to deal with the most complex cases.

5. Improved commissioning: approaches to commissioning which are most likely to improve services include:

- Creating clinical commissioning teams with a good mix of staff across primary and secondary care. Ideally with representation from the eye care sector and adult social care.
- Having clear, systematic processes for collecting patient feedback and using it to inform commissioning decisions. This will ensure services are patient focused.
- Using good quality data to inform commissioning decisions. UK Vision Strategy has produced a [commissioning guide](#) to assist commissioners through all stages of the eye care commissioning process.
- Designing and implementing more effective rapid referral pathways. This will be particularly beneficial if done uniformly, on a national scale.

Conclusion

In recent years, there have been significant advances in the treatment available to wet AMD patients and there are many examples of good practice across the country. Nevertheless the system still fails too many people and an ageing population will only add to the pressure on services. But by introducing more rigour into pathways, adopting new ways of working, better understanding patients' needs, and raising awareness of the condition, there is every prospect that, with sufficient resources, care can be improved.

2. Background

2.1 What is wet AMD?

There are two types of AMD, “wet” and “dry”. Both impact on the macula – a tiny area at the centre of the retina which is located at the back of the eye.

The retina is made up of photoreceptor cells which detect light, convert it into electrical signals, and then send the signals to the brain. The brain then interprets these signals as the images we see.

There are two main types of photoreceptor cell – cone cells and rod cells. Cone cells are concentrated around the macula and are responsible for central vision, seeing fine detail and most colour vision. AMD affects the macula area and therefore an individual’s central vision.

In dry AMD there is a gradual deterioration of the macula as cells die off and are not regenerated. With wet AMD the onset is much more rapid. When the cells of the macula stop working correctly the eye starts growing new blood vessels to fix the problem. These blood vessels grow in the wrong place and cause swelling and bleeding underneath the macula. This new blood vessel growth, medically known as neo-vascularisation, causes more damage to the macula and eventually leads to scarring. Both the new blood vessels and the scarring damage central vision and may lead to a blank patch in the centre of a person’s sight.

2.2 Prevalence and incidence

AMD is the most common cause of blindness in the UK (RNIB, 2013; Access Economics, 2009). There are over 500,000 people with the condition nationally. Approximately one tenth of these have wet AMD, accounting for 40,000 new cases per year (Owen, Jarrar, Wormald, et al, 2012).

The risk of developing either dry or wet AMD increases with age. In a small number of people, it can develop in the 40s and 50s but it is mainly a condition found in the over 65s. For those in their 90s there is a one in five chance of developing AMD (Owen, Jarrar, Wormald, et al, 2012).

2.3 Current and projected economic impact

The population aged 85 and over is the fastest growing age bracket in the UK and these are the people most at risk of developing wet AMD (ONS, 2012).

In 2010, the estimated cost of detection, treatment and provision of state and family social care for everyone with AMD was more than £1.6billion (Minassian and Reidy,

2009). This cost is expected to increase significantly both in real terms and as a percentage of NHS spending due to the increasing number of AMD patients.

2.4 Risk factors

The exact causes of AMD are not known but genetics, diet, a lifetime's exposure to sunlight and cardiovascular factors are all believed to have an impact on the likelihood of developing the condition. Smoking is a clear risk factor, with smokers twice as likely to develop AMD than non-smokers (Evans, Fletcher and Wormald, 2005).

2.5 Personal impact

The direct impact of wet AMD is a potential loss or a significant impairment of central vision. This has profound consequences for many patients, hampering their ability to carry out day to day tasks, as well as an obvious emotional impact.

2.6 Available treatments for wet AMD

2.6.1 Anti-VEGF treatments:

In August 2008, the National Institute for Health and Clinical Excellence (NICE) approved Lucentis (ranibizumab) for the treatment of wet AMD for use in the NHS in England and Wales.

This drug is known as an anti-vascular endothelial growth factor (anti-VEGF). It works by preventing blood vessels growing and leaking at the back of the eye. By stopping blood vessel growth and leakage, further sight damage can be prevented and in some cases sight can be improved.

Lucentis has to be injected into the eye by a technique called intravitreal injection. It needs to be given in an operating theatre or a "clean room" to avoid infection. Before the injection, the patient will be given anaesthetic eye drops to make their eye numb, an antibiotic drop to help prevent infection, and a drop to dilate the pupil.

Another anti-VEGF treatment, Eylea (aflibercept) has now been licensed for use in the UK. It is currently being evaluated for cost-effectiveness by the Scottish Medicines Consortium (SMC) and NICE. Directions on its use in the NHS will be published in the form of guidance by the SMC in April 2013 and NICE in August 2013.

Another anti-VEGF drug, Avastin (bevacizumab) is being used to treat wet AMD in some eye clinics. It is unlicensed and has never been approved for use in the eye. RNIB calls on commissioners and clinicians to stop using Avastin until its safety and efficacy have been thoroughly reviewed by the Medicines and Healthcare products Regulatory Agency (MHRA).

2.6.2 Photodynamic therapy (PDT)

Nearly all patients are now offered anti-VEGF treatment. In very rare cases some may be given photodynamic therapy (PDT) if they have wet AMD and other complications. PDT uses a light sensitive drug and a low energy (cold) laser to stop new blood vessels growing.

2.7 Current guidelines

2.7.1 Diagnosis to treatment guidelines:

Royal College of Ophthalmologists guidelines currently state that suspected wet AMD cases should be diagnosed within one week, and treated within a further week.

2.7.2 Treatment guidelines:

NICE guidance states that Lucentis treatment should commence with one injection per month for three consecutive months, followed by monthly monitoring of the patient's vision. If the patient's vision deteriorates, the clinician will decide whether a further injection is required. The interval between two injections should not be shorter than one month.

The licence for Eylea states that treatment should be initiated with one injection per month for three consecutive months, followed by one injection every two months. There is no requirement for monitoring between injections. After the first 12 months, the treatment interval may be extended based on the patient's vision and the clinician's judgement.

3. Patient journey: awareness and first symptoms

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3.1 General awareness of wet AMD

Levels of awareness of wet AMD among patients interviewed for this study were very low prior to diagnosis. More than half (63 per cent) said they were not aware of the condition prior to diagnosis. This accounted for all patients in the study including those who had dry AMD prior to developing the wet type.

Patients who had previously developed dry AMD were more likely to know about wet AMD prior to developing the condition, however, the difference was only marginal – 41 per cent of patients compared with 36 per cent.

Of those patients who had previously developed dry AMD and were aware of the wet type prior to diagnosis, most had heard of it because they knew someone with the condition, for example, a relative or a friend.

Table one: patients’ awareness of wet AMD prior to diagnosis

	Percentage (number) of patients not aware of wet AMD	Percentage (number) of patients aware of wet AMD
All patients whether they had or had not got dry AMD prior to developing wet AMD	63% (37)	37% (22)
Patients who did not have dry AMD prior to developing wet AMD	64% (27)	36% (15)
Patients who had dry AMD prior to developing wet AMD	59% (10)	41% (7)

In some cases, people were aware of wet AMD as a result of working in the health sector and in one case, a patient specifically reacted to an advert on wet AMD.

“I worked for the NHS and because I’d done my research I knew time was of the essence to start the injections to preserve my vision.” (patient)

“In the last week of September 2008, I saw an advert about wet AMD – the one with all the signs where everything goes crooked. I thought, hang on, this is what’s happening to me.” (patient)

3.1.1 Awareness of the two types of AMD (dry and wet)

There appears to be little understanding that there are two types of the condition that impact on the macula in different ways and have very different prognoses. Patients interviewed said that very little is done by the NHS to explain the differences between the two types.

“When I was told I had dry AMD that was it, I wasn’t told the possibility of getting wet even existed.” (patient)

“When I was diagnosed I was told that I had macular degeneration, but at no point was I told I specifically had wet macular degeneration, and I wasn’t aware that there were two kinds of macular degeneration till much later in my treatment.” (patient)

“I went to the hospital several times and they kept saying I had an age-related condition, but they never said the word “macula”. It wasn’t until I joined the Macular Disease Society that I learned the difference between wet and dry macular [degeneration].” (patient)

In one case a patient who had dry AMD assumed that their symptoms were caused by their current condition, without realising a “wet” form existed and that they could develop this too.

“Now it was just before Christmas and I noticed a change in my right eye, I couldn’t see very well but I could still see but it was slightly distorted. I just put that down to changes, I thought it was the dry AMD. Then just after Christmas it suddenly went and I couldn’t see anything in my central vision. It was just black and I could just see peripherally.” (patient)

3.1.2 Terminology and confusion about the condition

Some clinicians and commissioners felt that communication about wet AMD posed challenges because of the terminology of the condition.

“Most patients only know when they are diagnosed. Despite all the campaigns that have taken place. There are patients who come in and say they have never heard of it, probably because the name is peculiar. They say ‘Doctor, what did you say I had?’ I think that’s the problem but if we write it down for them and give them the booklet I think that’s very helpful.” (ophthalmologist)

3.1.3 Regularity of eye check-ups and knowledge of AMD

Most patients (94 per cent) said they had regular eye tests prior to diagnosis. Of those, more than two thirds had check-ups at least annually. Despite the high numbers there was no obvious relationship between regular sight tests and greater awareness of wet AMD.

Table two: percentage of patients who had regular eye tests prior to diagnosis

Regularity of eye test	Percentage (number) of patients
Every six months or more frequently	13% (7)
Every 12 months	50% (27)
Every 24 months	31% (16)
Less frequently than every 24 months	4% (2)

3.1.4 The need for awareness raising campaigns

Few clinicians interviewed were aware of any current national awareness raising campaign on wet AMD, although some mentioned previous ones by the Royal College of Ophthalmologists and RNIB. Many argued for public awareness campaigns so that potential wet AMD patients would know to act quickly upon identifying first symptoms.

Many highlighted localised effort, but this was typically local educational talks, often to existing patients, rather than raising public awareness more generally. Most clinicians felt that a wider public awareness raising campaign is essential.

“Sunderland has a macular support group. We do talks and educational evenings at the eye infirmary.” (ophthalmologist)

“As an optometrist myself I find it very challenging. If you ask anyone of all the senses which one would they fear losing most the majority of the public would say sight. But we are very British and put things off for another day. I think an awareness campaign, not necessarily run by optometrists but managed generically with impact and messages would help.” (optometrist)

“We still get patients saying they have left it too long, awareness raising needs to happen before they get to hospital.” (ophthalmologist)

3.2 Initial symptoms

Patients described their initial symptoms in a variety of ways. These included “wavy lines”, “zig zag lines”, letters in a crossword “dancing about”, “a net”, a “mauve” area, “cloudy” vision, a “glare”, a “black spot”, a “patch” or a “distortion”.

Subtle changes during the early stages of wet AMD make it extremely difficult for people to notice initial symptoms. This is compounded by the fact that good vision in the second eye compensates for the deteriorating vision in the other eye.

Late stage wet AMD is typically indicated by a significant deterioration in central vision, which is why patients describe it as seeing a “black spot”.

“I began to notice deterioration within my right eye, particularly when I started to see straight lines as zigzags and couldn’t line up where to pour milk into my cereal.” (patient)

“I would notice when I did a crossword that the letters started to dance about.” (patient)

“When I was out walking I found it difficult to focus on the ground in front of me and I struggled to get a sense of depth in my vision.” (patient)

“I was watching a football match on TV, at this point I noticed that the grass was green when viewed only with my right eye so I looked at several things with only my right eye and they were distorted.” (patient)

“I woke up one morning and out of my right eye I could see a sort of net in front of it.” (patient)

“My sight began to become quite mauve.” (patient)

“I got a clouding in the right eye and got worried about it” (patient)

“I was sitting on the couch and I was looking at a photo of my grandson, it just seemed as though something wasn't right. So I closed one eye, looked at it through one eye and everything was fine. I then did the same with the other eye and it was really dark, that dark that I was struggling to see his face.” (patient)

“The black patch on my eye was getting bigger.” (patient)

The fact that many patients may have only first noticed wet AMD symptoms at late stage highlights the need to raise awareness and encourage patients to check their vision in each eye regularly as they get older.

3.2.1 Rapid reaction to symptoms

Most patients reacted quickly to the symptoms of the condition once they noticed them. One or two patients also indicated their first action was to download an Amsler Grid – a chart with grid lines and a dot in the middle. It is used to check the vision of each eye and the grid lines appear distorted to someone with either type of AMD.

“I knew it might be a serious thing because of my left eye diagnosis, and I also knew that it would be best to act quickly to get the most out of treatment. I called my daughter-in-law and got her to take me to the hospital.” (patient)

“I talked to my husband who was at home with me. My husband downloaded an Amsler Grid. I looked at the grid and realised that must be the problem.” (patient)

3.2.2 Reasons for slow reaction to symptoms

In some patients, even after noticing symptoms, they procrastinated before acting. This appears to be because patients failed to understand the potential downside of not acting quickly and seemed to treat the deterioration in their sight as if it was not serious but something that could be solved with a new prescription.

“I sort of bided my time, but I felt things were getting worse, so I went back to the opticians and luckily got an optometrist whose thesis was on macular degeneration.” (patient)

“Spoke to my wife; she said I should go to the opticians if I couldn’t read. Took me three months to act and book an appointment with my regular optician [optometrist] in January 2011, seen him for about 20 years. Things just got in the way before Christmas, then I was busy with Christmas etc, so January was the first time I had a chance.” (patient)

“[It took] a month because I wasn’t sure that the problem merited going to the opticians at that point.” (patient)

In a small number of cases, patients who wore glasses also seemed to believe that the problem was their prescription.

“Because I’d recently got new glasses I assumed it was a problem with my prescription and did not suspect anything more serious at this point.” (patient)

Some patients also indicated they did not act rapidly because they did not want to “burden the system” or “make a fuss”. This is highly problematic as wet AMD normally develops rapidly over days and weeks.

“I think it was a good six weeks [until the patient went to the eye clinic] because at first, you see, it wasn’t that bad and I just put it down to changes. Because I hadn’t been told exactly what to expect, that was the thing. I didn’t want to appear to be overreacting because they said if it will bleed it will suddenly change and I’m looking for something in the mirror in my eye but there isn’t anything. I didn’t want to make a fuss really if it was just a natural progression. Then after this January I just knew that it wasn’t right.” (patient)

Some clinicians highlighted that men were less likely to act quickly to the initial symptoms than women.

“I think the most crucial part of it all is awareness. There are such simple symptoms and exercises that patients could carry out and look out for that would help pick up symptoms early. I think this is especially bad with men.” (optometrist)

4. Patient journey: diagnosis phase

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4.1 Speed of diagnosis

4.1.1 Presentation of symptoms

Most patients first present symptoms to a community optometrist (three quarters of the study sample) or their GP (15 per cent). Some attended the hospital accident and emergency department (eight per cent), often on the recommendation of their optometrist/GP. In a small minority of cases, wet AMD was spotted during a routine eye appointment with an optometrist or by a hospital consultant while the patient was undergoing treatment for another condition.

Patients are referred to the hospital eye clinic for diagnosis. Professionals, including optometrists and GPs, identify potential wet AMD cases and refer them to the hospital for diagnosis and treatment.

Table three: where patients first present

Healthcare setting/professional	Percentage (number) of patients
Accident and Emergency (A&E) Department	3% (2)
Optometrist	74% (46)
Hospital eye clinic	8% (5)
GP	15% (9)

4.1.2 Time taken from first contact to diagnosis

Royal College of Ophthalmologists guidelines currently state that suspected wet AMD cases should be diagnosed within one week by an ophthalmologist, and treated within a further week.

This study found that the time taken from first contact to diagnosis varied hugely, with 69 per cent of patients not receiving a diagnosis within seven days as recommended by Royal College of Ophthalmologists guidelines. A further 15 per cent took longer than 60 days to get a diagnosis.

Table four: time taken from first contact to diagnosis

First contact to diagnosis	Percentage (number) of patients
7 days or less	31% (18)
8-14 days	9% (5)
15-30 days	26% (15)
31-60 days	19% (11)
More than 60 days	15% (9)

Equally the study showed that time to diagnosis was not affected by where the patient first presented.

Table five: time taken from first contact to diagnosis by healthcare setting/ profession

	A&E	Optom	Eye clinic	GP	Percentage (number) of patients
7 days or less	0	12	3	3	31% (18)
8–14 days	1	4	0	0	9% (5)
15–30 days	1	11	1	2	26% (15)
31–60 days	0	8	0	2	19% (11)
More than 60 days	0	7	1	1	15% (9)

4.1.3 Patients’ perceptions of speed of diagnosis

There is a clear mismatch between patient expectations on speed of diagnosis and guideline recommendations. Largely because of a lack of patient understanding of the time a wet AMD diagnosis should take. The majority of patients interviewed whose diagnosis took between 31 and 60 days described the time as either “quite fast” or “very fast.”

Table six: actual time taken to diagnosis compared with patients’ perception of time taken

Actual time taken to diagnosis	Very fast	Quite fast	Not fast nor slow	Quite slow	Very slow	Number of patients
7 days or less	8	6	1	1	2	18
8–14 days	4	3	1	0	0	8
15–30 days	6	3	3	2	1	15
31–60 days	3	4	1	5	0	13
More than 60 days	1	2	0	0	5	8

4.2 Barriers to diagnosis

There are several challenges at the initial point of contact which can elongate the time to diagnosis.

4.2.1 Lack of knowledge and poorly designed referral pathways

While most optometrists and GPs are aware of the pathways and referral processes where wet AMD is suspected, this is not universally the case.

“We do have a local fast track service used by some of the opticians [optometrists] but not all of them. We have audited our referrals from the opticians. The ones who use the dedicated fast track form either by fax or by email, those patients tend to get seen a bit quicker. The urgency is stressed. With the fast track service, the opticians tend to send their patients on the same day or the next day.”
(ophthalmologist)

“There are a number of things that can go wrong there. First of all the optometrist might not suspect urgency, second of all they might not fax the letter through straight away, thirdly they might not highlight properly what they have in mind and it might be misinterpreted at the hospital by the person reading it. The faxes are read by the nurse, it could be incorrectly read and even if it is there may not be availability for an appointment. There are a lot of things that can go wrong there and this is one of the first problems.” (ophthalmologist)

GPs are generalists who typically see patients with wet AMD less frequently than optometrists. Some clinicians pointed out that in certain cases this can mean that GPs are more likely to make a general referral to a retinal clinic, rather than highlight suspected wet AMD, and this can cause a delay in diagnosis.

“If patients are referred initially to the general clinic and not the retinal clinic they definitely have a longer time and they may even have a much longer time because it depends on how it’s flagged up. GPs in particular don’t pick up the symptoms so they send a letter in saying Mrs Bloggs has got difficulty with her vision please see her and of course it could be anything – cataract, glaucoma, anything. And also they often don’t say that it’s recent onset of symptoms, they might assume that she’s had problems for years and so it’s not urgent. At that point it comes through a routine pathway and that can be quite slow quite frankly, because the pressure is on the urgent appointments not the non-urgent.” (ophthalmologist)

“Eyes are not an area of expertise for GPs and they will freely admit that optometry has clearly been allowed to develop and flourish in that respect.” (optometrist)

“It was very difficult to get to see an eye specialist who would be able to diagnose and treat me. It took more than three months which is totally unacceptable. The consultant was furious. I didn’t realise how serious the problem was and how much damage could be going on during those three months. If I had known I would have fought harder to be seen sooner. So I suppose it’s partly my fault as well.” (patient)

Awareness of the pathway and referral system processes are seen by clinicians as central to reducing the time to diagnosis and many argued that as well as raising awareness of wet AMD in the general population there was a clear need for specific education on the pathways and rapid referral procedures among professionals. In some cases education of optometrists appears to be more systematic.

“I think education, especially amongst GPs and optometrists, has to improve significantly. Moreover, I think the trust between GPs and optometrists needs to improve significantly; they have to have a better understanding between them about who is going to make the referral and have confidence that the other person will make the referral.” (commissioner)

“One of the specific questions we ask optometrists when we see them is ‘do you know about the fast track wet AMD?’ This is twofold. Really to make sure they know about it. We have 100 practices and 20 people with additional contracts to do home visits in Leeds. We have almost got around them all and I can’t remember the last time somebody said they didn’t know about the wet AMD fast track scheme.” (optometrist)

4.2.2 Poorly designed referral pathways

A particular problem for some patients was being referred from the optometrist to the GP before they could attend the wet AMD clinic, causing unnecessary delay. This is a reflection of poorly designed referral pathways.

In some cases, delays were caused by similarly ineffective referral pathways which call on professionals to send letters rather than faxes or emails.

“My optometrist referred me to the eye clinic; however, I had to go to my GP first to complete the referral procedure. My GP then referred me to the eye clinic.” (patient)

“In some parts of the country an optometrist has to refer the patient to a GP before they can then be referred to the hospital, and in other parts of the country an optometrist makes the referral. In the first part of the process there is something really key about people understanding what they are looking for and being very aware of the criteria.” (Commissioner)

“There are definitely bottlenecks – it depends how they get referred. The point at which they are seen in my triage clinic will depend on the referral letter. If they are

referred via the GP and the GP sits on the optometrist's referral letter for two weeks before they send them in then it can be three or four weeks before we see them. It also depends whether the referral is marked correctly as urgent. Whereas when optometrists fax directly, we can see patients within a week or two." (optometrist)

"It should be immediate – within a week or two weeks – but it's never like that because what usually happens is once they see the optometrist, the optometrist tells them to go to the GP, the GP doesn't fax the referral even though we have an emergency fax. They usually post the letter through so I would say on average it could take sometimes 30-40 days before they are referred." (ophthalmologist)

In one case a Primary Care Trust offered no wet AMD service within their area but still asked that patients be referred via its main hospital retinal department, only to be passed to a hospital outside the area.

"The PCT has decided that they are going to commission the service at neighbouring centres. This has been the case for years and there has been discussion about change – we are not really happy about this as it isn't a good deal for patients." (ophthalmologist)

4.2.3 Co-existing conditions

A minority of patients also had cataracts or other eye conditions and for them the diagnosis is more problematic. Co-existing conditions create challenges in the detection of wet AMD and subsequent referral. Generally older people are more prone to having more than one eye condition.

"I was first told when I went for a check up that I had wear and tear. I think the lady told me to eat more green vegetables or something like that. Then I had the cataracts done but nothing was mentioned then although my eye sight wasn't very clear. It was obviously beginning then in my right eye but nothing was mentioned." (patient)

4.2.4 Restrictive treatment guidelines

In certain cases patient's wet AMD was not developed enough to be treated. Current NICE guidelines stipulate that Lucentis should only be used when visual acuity is between 6/12 and 6/96. Visual acuity refers to the number of lines a patient can read on an eye chart which is one measure of how good a patient's vision is.

Two clinicians suggested the guidance should be reviewed so that patients can be treated before their sight deteriorates.

"The key is getting patients in with good vision. We know that if you start [treating the patient] with good vision you are more likely to maintain good vision. We need NICE to support treatment at this stage. At the moment, even if you get patients in really early, they may be too early to treat." (ophthalmologist)

The study also found that patients who are not yet eligible for treatment are not always followed up rigorously.

“He said that I had mild AMD in my right eye and he suggested that I come back a month later when it may be a bit worse and therefore treatable. At this point he tried to book me an appointment in a month’s time, but this was rebutted by the receptionist and she said I couldn’t have an appointment till August, which was six months away.” (patient)

4.2.5 The problem of over referral

As well as causing needless concern among patients, for clinics struggling to meet demand over-referral is an obvious problem. Some ophthalmologists highlighted that in their clinics over half of referrals do not have wet AMD and there is therefore a need to focus on improving the accuracy of referrals. However, they did highlight that it would be wrong for primary care professionals not to refer potential cases. They also noted the need for access to tools, such as Ocular Coherence Tomography (OCT), in the community to facilitate the identification of potential wet AMD patients.

“There needs to be a bit more education with the view to making the referrals more specific. Consistently only about 50 per cent of the referrals from primary care with wet AMD do actually have it. I think opticians in the main they are very concerned about missing something and so they do tend to err on the side of referring everybody who might have wet AMD with it. That doesn’t help the capacity problem.” (ophthalmologist)

“We do not always have enough capacity in the nurse consultant clinic because the referrals in are not of great quality. Often they say ‘please rule out wet AMD or suspected’ and I think we offer about 15 spaces a week and we diagnose about 6/7 a week – so more than 50 per cent are inappropriate. But you do not want to say to them to stop sending them in because that is wrong but the referrals could be of a higher quality.” (ophthalmologist)

4.3 Patient information leading up to diagnosis

4.3.1 Patients’ perceptions on information provision

Patients are more likely to say they are poorly informed about what is going on in the diagnosis phase than once they are receiving treatment. Some patients (34 per cent) reported that they were either “not well at all” or “not particularly well informed” during the diagnosis phase.

Table seven: how well informed patients were during the diagnosis phase

	Not well informed	Not particularly well informed	Quite well informed	Very well informed
Percentage (number) of patients	17% (8)	17% (8)	26% (12)	40% (19)

4.3.2 Clinicians' perceptions on information provision

Clinicians were, if anything, more likely to say their patients were “not particularly” or “not at all well” informed. Of those who were willing to offer an opinion, 46 per cent said they felt patients were either “not particularly” well informed or “not at all well” informed.

Some clinicians also stated that it is crucial that patients know what to expect. By making patients aware of the time a diagnosis should take, there is a much better chance they will act if the system fails them.

“People need to know what is going to happen to them and to know to complain if it doesn't because the awful thing – and you get this as a GP – people who have kind of heard nothing for four weeks and then they come in and say my eye is worse now and you just think oh no.” (GP and commissioner)

4.3.3 Patient empowerment and asking questions

For many patients there is a strong desire to know more about the condition and its treatment earlier in the process. However, some do not ask the questions they really want to at the outset and often feel daunted by the process.

“I didn't feel that it was ever made clear to me what the implications of having wet AMD were when I was referred to the hospital with glaucoma and wet AMD was spotted.” (patient)

“I didn't get much information from the hospital. I had to do my own research to find out things.” (patient)

“I would say it's not exactly explained to you what would happen. I know they don't know themselves really how it is going to progress from one person to the other but I would like to be more informed about it really because it is very, very frightening. I am the sort of person that would rather know than not know.” (patient)

“There are many patients, especially the elderly, who are often in awe of the doctor and therefore don't ask about the different treatments available and for more information about their condition. I do feel that there should be more emphasis on the care of patients with wet AMD.” (eye clinic liaison officer)

In terms of information, most patients praised healthcare professionals and highlighted examples of good practice, including being told early on that they may be receiving an injection. They also praised the strong communication skills of nurses. In many clinics nurses carry out the first assessment of a patient which provides an ideal opportunity to explain more about the treatment process.

“I was then referred to the Royal Blackburn Hospital where I saw a doctor. Prior to getting to the hospital I received a letter from them stating that it was possible that I would be having an injection on the day that I arrived.” (patient)

“They took time to explain what they are going to do. I found this very reassuring. The nurses especially were excellent.” (patient)

However, in some cases, patients are critical of the communication skills of professionals and felt they are given leaflets as a substitute for good verbal communication.

“Although the consultant is very good at what he does, his communication skills were not very good at all. When I was diagnosed with wet AMD, I asked him if I would go blind and he immediately responded that I would. It was only when I arrived home and got my son to do further investigation that I realised that blindness was by no means an inevitability. I would say I have found this with clinicians throughout; they’re very good at their job in terms of knowledge but not very good at communicating things. I have found on several occasions that they aren’t good at communicating and you just get given masses of booklets and paper.” (patient)

4.3.4 The need for emotional support

Some patients also wanted to be offered emotional support at the point of diagnosis.

“I felt isolated during the diagnosis process and needed someone to talk to regarding my diagnosis.” (patient)

“It might have been helpful to talk to other people who have been diagnosed with wet AMD, to attend a group or something, as it can be daunting at the beginning.” (patient)

“The part that needs to be improved the most is prompt support for patients, I am a wet AMD sufferer myself and I came through the ECLLO [Eye Clinic Liaison Officer] system. I feel if I would have prompt support and more information about what was going on I would have been more at ease. For example, you often have to wait a few weeks for treatment, but you are not told that this will not adversely affect your eyes. This stage of limbo can be terrifying, a little bit of advice and care could assuage your concerns.” (eye clinic liaison officer)

4.4 Quality of care up to diagnosis

Clinicians and patients gave similar scores for the quality of care received in the run up to diagnosis. Over half the patients interviewed (58 per cent) said the quality of care they received was “very good” and 21 per cent said “quite good”. This was similar to clinicians who marked care up to diagnosis “very good” (54 per cent) and “quite good” in (32 per cent).

Table eight: patients’ perception of quality of care up to diagnosis

Quality of care up to diagnosis	Percentage (number) of patients
Very good	58% (22)
Quite good	21% (8)
Average	16% (6)
Not very good	2.5% (1)
Not good at all	2.5% (1)

5. Patient journey: treatment phase

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5.1 Treatment timeframe

Royal College of Ophthalmologists guidelines currently state that suspected wet AMD cases should be diagnosed within one week, and treated within a further week. For many patients interviewed for this study (61 per cent) this was the case but for some it took longer to receive treatment. In fact, 18 per cent waited for 15 days or longer.

Table nine: time taken from diagnosis to treatment

Diagnosis to treatment	Percentage (number) of patients
Less than 2 days	40% (21)
3–7 days	21% (11)
8–14 days	21% (11)
15–30 days	15% (8)
31–60 days	0% (0)
More than 60	3% (2)

5.2 Receiving injections

Generally the thought of receiving an injection into the eye causes anxiety initially. However, many patients reported that the unpleasant thought was much worse than the reality. The consensus tended to be that injections are tolerable if they prevent sight loss.

However, for some patients receiving an injection into the eye is a particularly difficult experience.

“I have been on my own but a friend usually comes with me just in case. The first few times I was a bit shocked. I know that sounds silly because it’s only your eye but I did feel a bit wobbly. I’ve got used to it now. I don’t like it very much but it doesn’t hurt. It’s just uncomfortable and your vision is a bit blurred afterwards.” (patient)

“They could be a fraction slower, it feels a little too rushed after those drops – it is horrendous feeling of a shard being stuffed in your eye ball. But ten minutes later it’s better, maybe it’s just my eyes which react slower. It doesn’t get better, you dread having them. They are absolutely awful those injections.” (patient)

5.3 Interval between injections

5.3.1 Frequency of injections

Current NICE guidance states that Lucentis treatment should begin with one intravitreal injection per month for three consecutive months. This should be followed by a maintenance phase in which patients are monitored monthly for visual acuity (i.e. how many letters a person can read on an eye chart which is one measure of how good their sight is). If the patient’s vision deteriorates due to wet AMD, a further dose of Lucentis should be administered.

This study found that the frequency of injections given to wet AMD patients tended to decrease after the first three injections, sometimes for good clinical reasons but on other occasions due to capacity issues that put pressure on the appointments system.

Just over half of patients interviewed (53 per cent) said they received injections on a monthly basis, while just under a quarter (22 per cent) reported intervals of 42 days or more.

Table ten: frequency of intravitreal injections

Frequency of injections	30 days and under	between 31 and 42 days	more than 42 days
Percentage (number) of patients	53% (31)	25% (14)	22% (13)

5.3.2 Slippage in interval frequency

Greater priority is often given to the initial first three injections in wet AMD treatment in order to meet referral to treatment targets. This means patients already in the system have their follow-up appointments delayed. In some cases, clinics gradually stretch the time between injections to deal with insufficient capacity and in other cases, appointments are cancelled because clinics are struggling to keep up with demand. This slippage impacts upon patient outcomes as, if left untreated, wet AMD develops rapidly over days and weeks and causes permanent sight loss.

“One of the big issues we had was people’s follow appointments being changed in order to accommodate new referrals in the system. So in order to meet the referral to treatment time target at the front end of the system the patients at the back end of the pathway are sort of being pushed on so we quite often get people who are having their follow up appointments bounced because they are having to accommodate people who are new into the system.” (GP and commissioner)

“The main issue is that the NHS is struggling to provide monthly appointments so we’re not seeing optimal results due to this slippage and disease reactivation occurs when this slippage takes place.” (ophthalmologist)

“For the first three injections the normal time gap is four weeks, but after the third injection the injections are a bit more intermittent and it can be anywhere up to seven or eight weeks, depending on how busy we are.” (ophthalmologist)

5.3.3 Patients’ perception of interval frequency

Generally patients are not aware of wet AMD diagnosis and treatment timeframes. This is why they may believe they are receiving good care even when they are not.

However, this study found that some patients noticed that treatments were not frequent enough – six of the patients interviewed said they were “not often enough” or “nowhere near often enough”. Patients probably realised treatment frequency was insufficient due to the effect it had on their vision.

“I didn’t see the point in keep giving me injections that were six or seven weeks apart when it is obvious that I needed to have injections every four weeks, because once the four week period had elapsed my eye started to deteriorate. I don’t feel that the injection phase is systematic enough, I always felt that I was playing catch-up.” (patient)

Table eleven: patient’s perception of injection frequency

	under 30 days	between 30 and 42 days	more than 42 days	Percentage (number) of patients
More than often enough	3	1	2	11% (6)
Just often enough	26	9	9	78% (44)
Not often enough	1	2	2	9% (5)
Nowhere near often enough	0	1	0	2% (1)

5.4 Problems with appointment systems

Patients generally preferred as much certainty about future appointments as possible and many clinics, but not all, gave three monthly appointments for the first three injections at the outset of treatment. The study found that many clinicians were focused on managing demand and getting the patients to clinic in good time so that there were no gaps in their treatment.

“When I got to Southampton the appointments system worked very well, all my appointments were booked up six months in advance.” (patient)

“The key has been working with the admin team to ensure that patients are booked into the clinics in good time – not just giving them appointments weeks in advance because we have slots available, we need to make sure they get in on good time and, if the clinic is full, they go into the nurse overflow. It’s something we’ve looked at through audits and worked to put right.” (ophthalmologist)

5.5 One stop or two stop service?

There is a debate among clinicians about the relative merits of a one stop service (where a patient gets a scan to see if they need treatment and then receive treatment, if required, on the same day) or a two stop service (where a patient gets the scan and then comes back for injection at a later date if required). Many clinicians interviewed for this study held the view that what mattered more was managing overall capacity well and rigorous process.

“One-stop services for diagnosis and treatment on the day. There are pros and cons for both integrated and separated approaches though.” (ophthalmologist)

Many clinicians and commissioners described the advantages they perceived of having all core secondary retinal care under one roof, as this improves communication and makes capacity bottlenecks easier to deal with. This might better be envisaged as a decision-making and treatment nucleus, rather than the provision of all retinal services.

From the patient perspective, certainty of getting treatment the same day and reduced inconvenience was generally preferred, but this has to be weighed against the fact the process can mean waiting in the clinic for a longer time in a one stop service.

“It’s very, very good from start to finish. It’s a one-stop shop, so you have an appointment on the same day that you have your injection.” (patient)

“Now they have changed the system, splitting the appointment into two days, which hasn’t improved things, doubling the waits, why go twice, when once will do?” (patient)

“It has been divided into a two part process. It’s difficult to get the time off work, and I’m forced to take holiday.” (patient)

Some patients felt they had very long wait times.

“The other problem is the length of time it takes. They call to tell you the time of your injection the day before, which is good, but then when you get there you could be waiting for up to three hours. Other times it’s been very quick but it makes it very difficult to plan your day.” (patient)

“Traffic through the department is incredibly slow. You get in at nine and get out at four.” (patient)

In cases where patients have the condition in both eyes they describe being unable to receive treatment for both at the same appointment. This is because the eye drops used in their treatment led to blurring of vision in the treated eye. This causes additional burden as they will need to attend twice as many hospital appointments.

“They said I had it in my right eye as well, but they could not treat it while it was as bad as my left eye. They kept examining and I went up there again and the doctor started on the right eye. Then they offered to do both at once – but this would make it hard from me to get home, so I agreed to take it in turns.” (patient)

5.5.1 Burden of disease and transport needs

Patients with wet AMD face particular problems with travel to clinics. Most are elderly and some are infirm or have other medical conditions.

Many partially sighted patients interviewed relied on support to get to hospital, especially those whose sight had deteriorated as a result of wet AMD and were unable to drive. Many received assistance to and from the clinic through friends and carers but occasionally from the voluntary sector. Some partially sighted or blind patients used public transport to get to the clinic although some found this challenging. Others had to rely on hospital transport.

“I have to have one person drive me there; this rotates from friend to friend.”
(patient)

“We use a local charity who gives us lifts to any hospital appointments.” (patient)

“No-one accompanies me, it’s pride I guess. Family offer but I get a bus to the hospital and then they arrange a taxi to take me home afterwards, even after the injections.” (patient)

“I go by hospital transport because I’m not on a bus route and I am at the stage where I can’t cross the road by myself and so if I got a bus I wouldn’t know when to get off. It’s very, very good. The same thing goes when I go for the clinic but I can walk in there by myself and I just have to go to the ambulance station when I want to go home.” (patient)

5.6 Barriers to treatment

Capacity constraints in the clinic are also a barrier to care. These take many forms, including physical capacity, such as an absence of available clean rooms for injections and a lack of experienced staff.

5.7 Patient information during the treatment phase

Many patients are reverential towards authority figures – principally doctors – and are too overwhelmed by the process and potential ramifications of the condition to be assertive.

Patients often think of the questions they really have only before coming back for a subsequent appointment. Whilst many patients felt reassured by the presence of consultants, some described the mismatch between the professionalism of consultants in delivering care and their communication skills. They also noted the tendency amongst some staff to emphasise the importance of leaflets and posters over verbal communication. Nurses, eye clinic liaison officers, AMD co-ordinators and other staff can all play a bigger role in communicating what is happening to patients.

Despite these findings, patients generally felt much better informed during the treatment phase than the diagnosis phase and clinicians agreed that this was the case. Of the patients treated just 12 per cent said they were “not particularly well” informed during the treatment phase and none said they were “not at all well” informed.

One area a few patients highlighted as a weakness was when they did not have a follow up discussion after their scan to ascertain whether they needed an injection.

“We used to see someone immediately after tests, but the system has changed. I feel less informed as a result.” (patient)

“Nothing specific, you just don’t see anyone after your scan anymore, so left feeling uninformed about the result of the scan, which you had been in the past. The letter you get in the post afterwards does not contain this information, just info on next appointment.” (patient)

5.8 Patient’s perceptions of success of treatment

Patients have little knowledge of what to expect and therefore find it difficult to judge the service based on “rational criteria.” Some patients, who are now registered blind and whose diagnosis took considerably longer than Royal College of Ophthalmologists guidelines, described the quality of the care they received as “very good”.

Table twelve: patients’ perceived success of treatment

Success of Lucentis treatment	Percentage (number) of patients
Very successful	42% (22)
Quite successful	42% (22)
Neither	3% (2)
Not really successful	9% (5)
Not at all successful	4% (2)

6. Patient journey: additional support services

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With successful treatment patients can retain sight and live much as they did before. However, in rare cases where treatment is not successful, patients will need additional support.

6.1 Low vision and social services

Low vision services are not always fully integrated into the main pathway and are normally reliant on separate funding streams. They typically offer a thorough assessment of a patient's needs; provide a magnifier and advice on lighting and changes around the home to facilitate day to day living; and signpost patients to local voluntary support. Patients in this study noted that when low vision services work well they provide reassurance and one to one time at a critical point in the sight loss journey.

“More patients need access to low vision services and often they cannot get an appointment for three to six months, which is ridiculous.” (ophthalmologist)

“We have services that are provided through social care, but they are underfunded. There are two areas in ophthalmology I feel strongly about and I don't think we do half well as we should do: prevention and rehab. As a rule, treatment for diagnosed visual disease is very good, but we need significant improvement in prevention and rehab and we underfund them.” (commissioner)

“When I was first registered blind somebody came along and gave me a white stick and a magnifier, but that was about it.” (patient)

6.2 Emotional support needs

For patients losing their central vision, the emotional toll can be enormous. Some of the patients interviewed for this study talked about feeling depressed, anxious and emotionally distraught.

“It’s given me depression and anxiety. I am very worried about what will happen in the future with my second eye. I am currently on the sick with it. It’s just always on the back of your mind that you’ve got this thing wrong with you that can make you go blind.” (patient)

“I think it’s the emotional aspect that’s affected me the most. I wouldn’t say I’m depressed but I’m bordering on it. All my hopes and dreams for my retirement, because I’m retiring next year, I can’t see any future in it because all the things I like doing I need my central vision for. It’s no good to me. I know there are ways of seeing with eccentric vision [a method of learning to use peripheral vision] but at the moment I can’t visualise that.” (patient)

Another problem is that relatives and friends do not always appreciate what it is like to lose central vision.

“My family still don’t understand really and that is difficult. It’s horrible when you don’t recognise the people coming into your home and you can’t read.”

For some patients there are other effects of losing vision including visual hallucinations (Charles Bonnet syndrome).

“It wasn’t until I got talking to someone, another patient, at the opticians [optometrists] that anyone mentioned to me about Charles Bonnet syndrome. At first I thought I was going mad, now I know it’s just part of the disease. I didn’t mind the angels but I didn’t like the parrots. I think it would have been helpful if someone had said about it – I know not everyone suffers from it but occasionally people do.” (patient)

6.3 Eye clinic liaison officers

Eye Clinic Liaison Officers (ECLOs) work closely with medical and nursing staff in the eye clinic and the sensory team in social services. They provide those recently diagnosed with an eye condition with the practical and emotional support they need to understand their diagnosis, deal with their sight loss and maintain their independence. Most importantly, they have the time to dedicate to patients following consultation, so they can discuss the impact the condition may have on their life.

Many clinics now have ECLOs to help patients and one explained their role in the process:

“Basically it means supporting patients on a social and practical basis, with regard to their sight loss and passing them on to external organisations – social inclusion, social activities, benefits advice. I’m like the person in the middle who can refer them on to external organisations who can help them with any issues raised.” (ECLO)

Some patients and clinicians also spoke about the value of this role.

“Eye Clinic Liaison Officer? Yes, we have one at Blackpool and she’s very good. She’s been at the other end of the phone a lot and has been very helpful.” (patient)

“She (ECLO) has been here to see us and speak to us all. I think it is a good idea to have here because people have little knowledge about this. I am lucky because I go on the internet and things but other people get very confused and isolated. I think the liaison officer is a very good idea.” (patient)

However, some ECLOs struggle to be integrated into the clinic set up and not all clinicians refer patients to them.

“We do have a high profile but it is possible that medical staff are cautious at a time when medical staff might feel it is sensitive; this is my perception.” (ECLO)

Some ECLOs argued that patients should be offered an opportunity to talk to them at the point of diagnosis, rather than later if they need to be registered blind.

“The ECLO needs to be involved earlier in the process, especially when a patient is diagnosed with wet AMD. I believe that patients need to be referred to the ECLO quicker and more patients need to be referred to the ECLO.” (ECLO)

6.4 Patient support groups

For many patients support groups are useful and for some vital.

“I do go to a group where we all have the same condition and it helps to hear other people talk and it helps for people to bring in new ideas. My family are very good, if I need to order things they do that, and they take me shopping. I’m very lucky in that way, so I’ve never sought any outside help.” (patient)

“Thankfully, I called the RNIB and they said I wasn’t going blind and they explained the support and help I could get. I went to their low vision service and there was a man who was 100 times worse than me and he was using a computer, that raised my spirits.” (patient)

“I am in touch with the local macular society. I go to monthly meetings with them and they also provided me with a big print diary. I know they offer lots of other things as well but I don’t feel I need them right now. My husband and I manage alright on our own at the moment.” (patient)

6.5 Assistive technology

Technology plays an important part in helping patients continue to live fulfilling lives. Some also patients got great support from councils who came around and helped with adaptations to their home.

“I’ve got myself a tablet which has proved invaluable. It means I can read a book again.” (patient)

“I loved to cook and have had to really adapt the way that I do that – I’ve got talking scales now.” (patient)

“I have a subscription to the RNIB talking books. It is a life saver for me.” (patient)

“The council checks in once a year. I am also in contact with Croydon Voluntary Association for the Blind. I’m not using their services too much at the moment because I have such a supportive family that I don’t need to, but I may use them in the future and it’s good to know that they’re there. One really good thing they do is send me a CD once a week from the local newspaper so that I can listen to all the local news. It’s a brilliant service.” (patient)

“The low vision service at the opticians have lent me the reader on loan and I don’t need to pay for it. It would be good to have an allowance so that I can look to buy keyboards and other things like that to help me use the computer as the costs can be expensive. Or maybe have some kind of loan service where you can use things but then swap them over if your eyesight gets worse.” (patient)

“I was very fortunate that the sensory team came into my house and modified several of my household utilities to my needs. So, yes I feel that the support has worked well” (patient)

7. The carers' role in the patient journey

The role of a carer varies hugely and depending on relationships, life circumstances, and critically the level of care needed. Some patients interviewed, particularly those whose vision has not deteriorated significantly, felt they did not need support.

One common role that carers provide in the diagnosis and early treatment phase is to support the patient in finding out about the condition and being assertive on their behalf.

“I have been primarily responsible for finding information on the condition and using that information to make sure he is getting the proper treatment.” (carer)

“I struggled to accept it for a while so I didn't ask any questions at first but luckily my husband did, so that was helpful.” (patient)

Clinicians also felt the central role played by carers in asking questions was critical. They also believed carers reassured the patient when they felt bewildered by what was happening to them.

“Some patients lack an understanding. The best case is when relatives attend with them because they grasp it. You can see them walking away saying ‘mum or dad, it's like this...’ and its ongoing education for the patient. Recall in younger patients is such a small percentage, in older patients it will only be less. If they are accompanied, I often ask them to come into the room with the patient.” (ophthalmologist)

“The system tends to favour younger people, and those with family members, who are inquisitive. It is definitely doesn't favour the elderly.” (eye clinic liaison officer)

Many carers provide a functional role, particularly ensuring the patient gets to appointments and back home again.

“My role as a carer has been to make sure she gets to her appointments on time and to generally provide any support that she might need.” (carer)

Where patients suffer from significant sight loss or are registered blind a carer's role becomes more profound.

“She finds it very difficult to see and finds it difficult to get up the stairs. Most of what would be described as my caring is just helping her out with day-to-day tasks such as getting up the stairs, going to the shops and getting into a car, that sort of thing. In the house I don't have to do much for her, other than help her upstairs.”

Many wet AMD patients have other conditions too that mean they rely almost totally on their carer. Typically where a carer is a spouse, and the patient has suffered significant sight loss, they support the patient around the clock.

“I already had arthritis before the wet AMD, so my husband was already taking a very active role. Nowadays he is my eyes.” (patient)

“I go everywhere with him.” (carer)

For many the emotional support provided is every bit as important as the functional support.

“My mother doesn’t live with me, so I only see her intermittently through the week. She still lives quite an independent life and she is 91, but she does need me there to support her with different things, like shopping. I probably offer more emotional support than support with day-to-day tasks.” (carer)

Some wet AMD patients are carers too.

“My social worker came to see if I needed anything else but I manage by myself. I have to because I’m a full-time carer for my wife, if I can’t cope then she would have to go into a home and I don’t want that. I have a bit of extra money through the invalidity allowance so I’ve bought things to make my life easier.” (patient)

8. Commissioners

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8.1 Commissioning wet AMD services

Most commissioners cover a broad range of services, such as “all of acute care” and many are overstretched and find it is difficult to keep up with the latest developments and best practice. Retinal care is only a very small part of their work, with wet AMD an even smaller subset. This often means priority is given to “worst first” and the relatively recent improvement in the available treatment for wet AMD means commissioning of this service has not been prioritised in some places.

There are clear gaps in commissioning provision, both in terms of capacity to commission (for example, having no one responsible for commissioning in post or more typically someone covering a very broad range of services) and due to insufficient information on which to base informed judgements.

“There’s no one to do it. There is a commissioning manager responsible for ophthalmology and other specialities, that’s the whole of ophthalmology. Ophthalmology as a whole is about two per cent of my job and wet AMD about 10 per cent of ophthalmology.” (commissioner)

Commissioners tended to argue that it was difficult to see wet AMD services as separate from wider retinal services.

“The key is to look at wider ophthalmic services rather than specifically at wet AMD services. If you are able to raise the standard of ophthalmic services across the board this will inevitably raise the standard of wet AMD services. However, if you have an eye department that just has good wet AMD services this will inevitably be dragged down if the hospital has a poor cataract service or poor retinal service. In most cases macula services are not independent within the eye department, which means that raising standards across the board is essential to raising wet AMD standards.” (commissioner)

Many commissioners are introducing clinician groups made up of clinicians from across secondary and primary care to try to better integrate services.

“We have within the health board an eye care group which meets on a quarterly basis, looking at ophthalmology and optometry, to look at opportunities to work between primary and secondary care and discuss the developments in the various sectors. That group is also responsible for commissioning services from optometrists but not from a secondary care perspective.”

“The eye care group is made up of ophthalmologists, the directorate team, optometrists, community optometrists and orthoptists and a representative from RNIB.”

8.2 Clinical Commissioning Groups

Currently many senior clinicians have no contact with commissioners, only with hospital managers, and monitoring and evaluation of wet AMD services is patchy. However, some highlighted that the transfer of powers to Clinical Commissioning Groups from April 2013 will have real advantages. Interviewees felt this is because clinicians relate to one another and that now the commissioner will command more authority.

Most of the commissioners interviewed in this study now commission services through Clinical Commissioning Groups (CCGs). However, some rely on Commissioning Support Units (which support clusters of CCGs) and a minority are still commissioning from Primary Care Trusts (PCTs).

Some commissioners emphasised their concerns about the upheaval caused by the move from PCTs to CCGs.

“There is a bottleneck within PCTs which is capacity. I think a lot of PCTs have tried to change the way they provide their services but have started to swim in treacle as they move to be CCGs.”

However, 28 per cent of the commissioners surveyed thought that the move to CCGs would make it easier to commission services, and none thought it would make it more difficult, so concerns were more about the transition than the destination.

8.3 Robust data to inform commissioning decisions

Most commissioners and clinicians underlined the importance of good data. Interviewees noted that electronic medical records provide a clear route to more systematic information that can be shared with commissioners, and can help clinicians organise clinics more rigorously based on good data analysis.

“We have the softer data that comes in so we’ve got one-to-one meetings with the service managers so we have qualitative data. I also get copied into any complaints

around eye care services and also have quite close relationships with the clinicians themselves so they feel able to tell me any problems with the service that are going on.” (commissioner)

Over half of the commissioners (56 per cent) said their commissioning board did not receive regular reports about the performance of eye care services or information on eye health issues, 41 per cent said that they did and 3 per cent did not respond to this question.

8.4 Patient involvement in commissioning decisions

Patient feedback currently plays a limited role and is not collated in some clinics, even though small changes in practice can make a big difference to the view patients have of their care. Some commissioners and ophthalmologists suggested there was a need for patient feedback.

“Patient feedback is not done terribly well. I recommended recently that we do more of this.” (commissioner)

A couple of clinicians went further and argued for patient representation rather than merely incorporating patient feedback.

“I could see that in the ideal world you might want to try and get the clinicians and commissioners involved as well as the management. I suppose you might also want some patient representation on there. I suppose as a first step it might be good to get a bit more of the clinician input.” (ophthalmologist)

8.5 Future demand for wet AMD services

Almost all commissioners felt that demand for wet AMD services would rise in the future, either slightly (55 per cent of commissioners) or a lot (38 per cent).

Table thirteen: future expectation of service demand

Future expectation of service demand	Commissioners
Rise a lot	38% (11)
Rise slightly	55% (16)
Stay the same	7% (2)
Fall slightly	0

9. New ways of working

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While the development of intravitreal drugs has greatly improved wet AMD services, there is a clear need for more resources.

Well organised wet AMD services are currently meeting treatment guidelines for most patients in many parts of the country, but some are not. An ageing population and new treatments for eye conditions such as diabetic macular oedema mean that pressures on retinal services will grow in the future.

New developments and innovation are therefore vital in ensuring services meet these increasing demands. The Action on AMD group provides a comprehensive analysis of best practice approaches to innovation, pathways and patient care across the UK (Amoaku, 2012).

9.1 Providing services in the community

Many commissioners and clinicians interviewed said that it was vital to provide more services in the community to relieve capacity bottlenecks in clinics.

“The increase in community provision should increase capacity as a whole and will have a positive impact on the provision of care for wet AMD patients.”
(commissioner)

A major area of innovation is the placement of Optical Coherence Tomography (OCT) scanners in key community optometrist locations. A few community optometrists now have OCT scanners available and with the right training these can improve the chances that wet AMD is identified accurately.

“Access to OCT equipment in the community or in health centres/satellite clinics – this would hugely improve patient diagnosis.” (ophthalmologist)

Some clinicians underlined the possibility that ophthalmologists could receive images of the macula remotely from community optometrists to help make better judgements about likely diagnosis at the outset. This can reduce unnecessary referrals for diagnosis

and prevent bottlenecks in the pre-treatment phase. This approach can also be used during the treatment phase to establish whether a patient needs to go to hospital for an injection or not.

“I know a number of pathways around the country where they are using optometrists. The optometrists have an electrical link with hospitals and can almost liaise in real time with the ophthalmologists and let them know what their findings are. Only the patients that need to have the follow up injections then go to the hospital to be followed up.” (optometrist)

While more OCT scanners in community settings are desirable not all community optometrists will be able to afford them.

“We have fundus examining lenses, a slit lamp, and access to dilating drops if they’re needed. However, we do not have access to a retinal imaging system; sadly we do not have a fundus imaging camera or an OCT scanner. They are both expensive bits of kit and while it would be useful to have them we simply cannot afford it.” (optometrist)

9.2 Exploiting multidisciplinary working and skill mix

In many parts of the country, multidisciplinary working is being explored more fully.

The staffing mix varies in different clinics, with some more reliant on ophthalmologists and others using a greater mix of staff. A simplified distinction is between clinics in which ophthalmologists are hands on for almost all patients and those where the ophthalmologist acts more as a conductor than member of the orchestra – relying on well trained specialist nurses and optometrists to deliver services; and agreeing the rules about when they should be involved rather than seeing every patient every time. The latter has clear advantages in terms of resources and can mean that for patients whose condition has stabilised clinics can be run largely by specialist trained nurses.

“The number of medical staff with retinal expertise is limited – we need to involve other staff and develop a more multi-disciplinary approach through service redesign.” (ophthalmologist)

Nurses and optometrists are taking on a greater role, including running clinics for patients whose condition has stabilised.

“The virtual review clinics were introduced about 18 months ago and initially patients didn’t like it but now it is just the standard process. The great benefit is that it is very, very quick for them – they can be in and out within half an hour. They don’t have to hang around for a doctor to see them. They are in every four weeks and maybe nine times out of 12 they’ll come back to get treated but again that process is very quick and they’ll be in and out within half an hour. I think communication can break down a bit with the virtual clinic if they don’t see a clinician and they see

a nursing technician but we have a system where they make a note on the patient's record that says 'patient wants to talk to doctor/clinician' and we just pick the phone up to them. So out of the 20 patients we've seen this morning, I've called two that have requested." (ophthalmologist)

Some clinics are beginning to explore or are implementing an approach in which trained specialist nurses carry out intravitreal injections. There are mixed views about this among ophthalmologists and, to an extent, among patients, but also some potential resource advantages.

"In some hospitals there is work being done on nurses giving the injections. The three hospitals which are most relevant are west of England, Sunderland and Moorfields." (ophthalmologist)

9.3 Using electronic records

Some clinicians also highlighted the importance of using the patient electronic records software (Medisoft is used by many ophthalmology departments) to be able to analyse patient records and audit performance.

Electronic records help ophthalmologists plan and redesign their service around different types of patient, with stable patients managed by nurses and optometrists, active patients managed by ophthalmologists and new patients managed by ophthalmologists or nurse consultants.

"Online records and good risk stratification are essential." (ophthalmologist)

"E-referrals and dedicated clinics for AMD and pre-formatted documentation. We have introduced these things here and it makes it quicker for clinicians in doing admin and easier for secretaries. Notes are completed using pre-formatted sheets that we have developed – this helps with audit, makes sure we take the correct details to get an accurate history (smoking, cardio-vascular) and contains prompts to give specific information. Everyone knows what they need to check and it's a low cost solution." (ophthalmologist)

9.4 New treatments

A new anti-VEGF treatment, Eylea (affibercept), is currently being appraised by the Scottish Medicines Consortium and the National Institute for Health and Clinical Excellence. It potentially offers a less onerous monitoring and treatment regimen and could assist eye clinics in meeting demand.

Furthermore, a large body of research is currently under way to develop new diagnostic and therapeutic interventions that require less frequent observation and treatment.

10. Management of wet AMD in the devolved nations

10.1 Scotland

In Scotland, The Scottish Eyecare Group, an alliance involving Optometry Scotland, Eyecare Scotland and RNIB Scotland, has supported the rollout of the integrated electronic referral scheme. The scheme, which was piloted by NHS Fife, has dramatically improved referrals to eye clinics through the use of digital images from community optometrists. The Scottish Government supported this development with a £6.6m investment.

In the autumn of 2012, the Government established a short-life “demand and capacity” working group on AMD Services involving representatives from Eye Care Scotland, Health Boards, senior civil servants, information analysts and RNIB Scotland. The aim of the working group is to:

- identify pressure points in AMD Services in Scotland
- acknowledge and share best practice within Scotland and from across the UK
- recommend actions and potential service reforms

A survey of AMD Services, including challenges and opportunities, has been compiled by Eyecare Scotland following consultation with clinicians. The survey is currently being piloted and will then be circulated across hospital eye care services. Following analysis site visits will be arranged. These are likely to take place in spring 2013 and will focus on both areas of good practice and areas of high pressure. Once the site visits have been held and the findings debated, a report will be compiled for consideration by the Scottish Government.

10.2 Wales

NHS Wales has adopted a nationally agreed AMD pathway which is being implemented in each health board.

The health boards are responsible for the planning and delivery of primary and secondary care in Wales, including the delivery of hospital care and some community services. The health boards’ performance is regularly audited against the national pathway for wet AMD by the Delivery and Support Unit for Wales.

Some health boards have established eye care pathway groups, which involve a range of managers, clinicians and other representatives (including RNIB) who meet regularly to discuss the integration of primary and secondary care and discuss developments across ophthalmology and optometry for the main eye conditions.

10.3 Northern Ireland

The Health and Social Care sector in Northern Ireland has designed services to meet NICE criteria. The Health and Social Care Board, which operates jointly with the Public Health Agency in Northern Ireland, is responsible for commissioning services for the local trusts. There is a national Specialist Services Commissioning Team, which offers advice on macula services including wet AMD.

The Specialist Services Commissioning Team is a multidisciplinary team involving a range of staff, including public health, nursing, pharmacy and commissioning. A macula sub-group has been established, involving staff from provider trusts and the RNIB, which advises on care pathways and where the pressures are in the service.

11. Conclusions

In recent years, there have been significant advances in the treatment available to wet AMD patients and there are many examples of good practice across the country but the system still fails too many patients. An ageing population is likely to add to the pressures on wet AMD services. By introducing more rigour into pathways, adopting new ways of working, better understanding patients' needs, and raising awareness of the condition, there is every prospect that, with sufficient resources, care will improve in future years.

This study shows that awareness of wet AMD remains dangerously low; close to two thirds of the patients we interviewed were not aware of it when they were first diagnosed. Given the importance of acting urgently and the fact that for most patients intravitreal injections can prevent loss of sight, raising awareness should be seen as a priority.

Clear empathetic communication about what is going on, particularly in the diagnosis phase, where patients have limited knowledge of what to expect, is vital. By making patients aware of the time a diagnosis should take as well as the wet AMD treatment pathway, there is a much better chance they will act if the system fails them.

Many patients get a slower diagnosis as a result of either lack of knowledge of rapid referral procedures or ineffective referral pathways. Where optometrists and GPs are familiar with local rapid referral systems and they are effective, patients are likely to get a quicker diagnosis.

In many areas of the country capacity is unable to meet demand. The consequences of this include delayed appointments and less frequent injections for patients, both resulting in sub-optimal care. While greater funding is clearly part of the solution (particularly going forward as the population ages) there are some best practice approaches that can relieve pressures on the system.

One model is placing optical coherence tomography (OCT) scanners in key opticians (optometrists) in community locations. The diagnosis pathway would point patients to these community settings and OCT scans could be sent electronically to a hospital for ophthalmologists to determine (with the optometrist) whether referral to the wet AMD clinic is necessary. Other new ways of working rely on utilising the multidisciplinary team rather than ophthalmologists seeing every patient every time. Some clinics are also beginning to use nurses to carry out intravitreal injections or run clinics for patients whose wet AMD has stabilised.

Weaknesses in commissioning wet AMD services are also causing clear problems. Approaches which are most likely to improve services include designing and implementing more effective rapid referral schemes (especially if done uniformly, on a

national scale); using good quality data and patient feedback to inform commissioning decisions; and creating clinical commissioning teams with a good mix of staff across primary, secondary and social care.

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Appendix one: methodology

Initial desk research was undertaken to understand the condition and its treatment in the UK. Various experts were consulted on an informal basis to provide insights and inform the qualitative research.

In-depth telephone interviews were then conducted with 163 people across the UK including patients, carers, commissioners, clinicians and others who work in the clinical environment. The interviews typically lasted over half an hour and sometimes considerably longer and comprised a mixture of open and closed questions. All interviews were conducted between 1 September 2012 and 31 January 2013.

The patients and carers who took part in the research either responded to RNIB national advertisements calling for wet AMD research participants or were identified through local branches of the Macular Society. All clinical staff, commissioners and other health professionals who took part in the research were contacted independently by The Campaign Company. All participants took part voluntarily and anonymously.

Interviews were conducted with 95 patients, 62 were diagnosed and treated after the introduction of Lucentis in 2008 and 33 prior to this date. Most of the findings and all of the statistics in the main body of the report relate to the 62 patients treated with Lucentis. The age of the patients interviewed ranged between 55-93 years with an average age of 77. In terms of gender split, 74 were women and 21 men.

In terms of healthcare professionals, 37 interviews were conducted and included two GPs, 10 community optometrists, two in-hospital optometrists, and 23 ophthalmologists. All are currently working within wet AMD services in the UK.

In-depth interviews were conducted with 12 commissioners and this was supplemented by an additional survey, sent to commissioners in England, which received 32 responses.

Eight eye clinic liaison officers, two AMD coordinators, and nine carers were also interviewed as part of the research.

Interviews were transcribed and uploaded onto NVivo and the responses to closed questions placed into a data framework.

The following table provides a breakdown of the interviews that were conducted for this study:

	England	Wales	Scotland	Northern Ireland	Total
GPs	2	0	0	0	2
Optometrists	11	0	1	0	12
Ophthalmologists	19	3	1	0	23
Commissioners	9	1	1	1	12
Patients	80	6	5	4	95
Carers	5	0	1	3	9
ECLO	8	0	0	0	8
Other NHS Staff	2	0	0	0	2
Totals	136	10	9	8	163

Appendix two: interview scripts

This appendix provides the interview scripts used for this study. It is broken down into patients, carers, healthcare professionals (used for clinicians, optometrists, GPs, ECLOs and other working in the healthcare environment) and commissioners.

Patient interview script

Section one: pre-diagnosis

- **Question one:** in the few years before your diagnosis how would you describe your general state of health? Did you have any long term conditions or eye conditions, including dry AMD?
- **Question two:** did you have regular eye check-ups? (Prompt: the NHS recommends sight tests every 2 years)
- **Question three:** before you noticed a problem with your sight did you know about wet AMD – yes or no?
- **Question four:** how long ago was it when you first noticed that something was not right?
- **Question five:** what did you first notice?
- **Question six, part one:** what did you do at that point? (Prompt: did you contact a doctor, call the NHS, go to an optometrist, or speak to a friend?)
- **Question six, part two:** if you went to a friend or family member, who was this? What did they suggest? Did they mention wet AMD? How long did it take before you spoke to them to nearest day?
- **Question six, part three:** if you went to a medical professional (a nurse, doctor, optometrist etc), who were they? how long before you saw them to the nearest day?
- **Question six, part four:** how long do you think it was before noticing your sight was not right to seeing a medical professional to the nearest day?
- **Question six, part five:** why did you see this professional (e.g. GP or optometrist)? (Prompt: was it your regular one?)
- **Question six, part six:** was it easy to get an appointment with the optometrist/GP?

Section two: the diagnosis phase

This stage is about how you were diagnosed after you saw the first healthcare professional

- **Question seven, part one:** who did you see next (make a note if the first person they saw diagnosed)?
- **Question seven, part two:** how long after seeing the optometrist/doctor was this?
- **Question seven, part three:** was it easy to see this second professional? (Prompt: was the process clear, did you get the right help, was someone with you)?
- **Question eight, part one:** can you explain what happened on the day you saw “x” medical professional? (Prompt: drops/ examination (slit lamp)/ fluorescein angiogram / injection/ dye/ photographs/ Optical Coherence Tomography?)
- **Question eight, part two:** were any other professionals involved in the process? (Prompt: e.g. nurse/consultant)
- **Question eight, part three:** where did this take place (Prompt: clinic/hospital/ mobile clinic)?
- **Question nine, part one:** Were you given a diagnosis then – yes or no?
- **Question nine, part two:** if not, how many additional days did you have to wait?

Section three: strengths and weaknesses up to diagnosis

Thinking about the process leading up to and including the diagnosis can you answer these questions?

- **Question ten:** how did you feel about the diagnosis process?
- **Question eleven:** how well informed did you feel about what was going on – very well, quite well, not particularly well or not at well at all?
- **Question twelve:** what were the things you felt you were not informed about?
- **Question thirteen, part one:** at the point of diagnosis, did the doctor give you a choice about the treatment options – yes or no?
- **Question thirteen, part two:** were these choices explained clearly? What was the process? Did they show you written information etc?
- **Question fourteen:** was the quality of the care very good, quite good, average, not very good or not good at all?
- **Question fifteen:** what could have been improved?

- **Question sixteen:** thinking about the whole diagnosis process from start to finish do you feel it was very fast, quite fast, neither fast nor slow, quite slow or very slow?
- **Question seventeen:** what things could have been improved to speed up the time taken?

Section four: the treatment phase

This section is about the treatment or treatments you received after diagnosis

- **Question eighteen, part one:** what treatment or treatments were you offered when you were diagnosed?
- **Question eighteen, part two:** how soon after you were diagnosed did you begin your first treatment to the nearest day?
- **Question eighteen, part three:** were you offered any other treatments at a later date?
- **Question nineteen:** do you feel that treatment “x” was very successful, quite successful, neither, not really successful, not at all successful? (Prompt: the treatment may have worked but only slowed progression. Patients may believe their sight should be restored)
- **Question twenty:** how frequently have you been given this treatment to the nearest day?
- **Question twenty one:** (if relevant) who administers the injections? (Prompt: a consultant?)
- **Question twenty two, part one:** over what period did this treatment last?
- **Question twenty two, part two:** are you still receiving this treatment?
- **Question twenty three, part one:** what was your overall experience of this treatment? (Prompt: on the process, the appointments system, the clinician involvement etc)
- **Question twenty three, part two:** where did the treatment take place?
- **Question twenty three, part three:** did anyone usually accompany you?
- **Question twenty four, part one:** along with this treatment, did you have regular follow-up appointments?
- **Question twenty four, part two:** what took place at these appointments?
- **Question twenty four, part three:** who were they with, what was their position, was it the same person?

- **Question twenty four, part four:** were there any problems? (Prompt: could anything be improved?)

Note: repeat relevant parts of questions 18–24 for each treatment

Section five: strengths and weaknesses of treatment

During the treatment phase can you tell us about your views on the following?

- **Question twenty five:** how well informed did (do) you feel about what was (is) going on? Very well, quite well, not particularly well or not at all well?
- **Question twenty six:** what were the things you felt you were not informed about?
- **Question twenty seven:** did (do) you feel that the quality of care through the treatment was (is) very good, good, OK, not very good or not good at all?
- **Question twenty eight:** (where relevant) the frequency of my treatment was more than often enough, just often enough, barely often enough, not really often enough, or nowhere near often enough?
- **Question twenty nine:** what (can) could have been improved?

Section six: adaptations, support and lifestyle

- **Question thirty:** please tell us about how wet AMD has affected on your life?
- **Question thirty one:** what adaptations have you had to make?
- **Question thirty two:** have you had any additional support such as counselling, social services, rehabilitation or low vision services? Please tell us about these?
- **Question thirty three, part one:** did you see an Eye Clinic Liaison Officer?
- **Question thirty three, part two:** (If no) were you informed that the service was available?
- **Question thirty three, part three:** (If yes) did you find that the service helped?
- **Question thirty four:** what parts of this support have worked and which need improvement? What has been the role of your carer?
- **Question thirty five:** have you felt informed about where to get help?

Carer interview script

- **Question one:** what is your relationship with patient “x”?
- **Question two:** have you been able to be there to support them through the whole process from before the diagnosis?
- **Question three:** can you tell us what it has been like being a carer of a wet AMD patient?

Section one: pre-diagnosis

The first section is about before patient “x” was diagnosed with wet AMD.

- **Question four:** in the few years before their diagnosis how would you describe their general state of health? (Prompt: did they have any long term conditions or eye conditions, including dry AMD)
- **Question five:** did they have regular eye check-ups? (Prompt: the NHS recommends sight tests every 2 years)
- **Question six:** before they noticed a problem with their sight did you know about wet AMD – yes or no? If yes, where did you find out about it?
- **Question seven, part one:** how long ago was it when they first noticed something wasn't right? Did they tell you when they first noticed – yes or no?
- **Question seven, part two:** (if yes) what did you do at that point?
- **Question eight, part one:** how long do you think it was before patient “x” noticed their sight was not right to seeing a medical professional to the nearest day?
- **Question eight, part two:** why did they see this professional? Was it their regular one?
- **Question eight, part three:** was it easy for them to get an appointment? (Prompt: was there a long wait, was the appointment system easy to use)

Section two: diagnosis

This stage is about how they were diagnosed after they saw a medical professional

- **Question nine, part one:** who did they see next (Prompt: make a note if they the first person they saw diagnosed them)?
- **Question nine, part two:** how long after seeing the first healthcare professional was this?
- **Question nine, part three:** Was it easy to see this second professional (Prompt: was the process clear, did they get the right help)?

- **Question ten, part one:** can you explain what happened on the day they saw x medical professional? (Prompt: drops/ examination (slit lamp)/ fluorescein angiogram / injection/ dye/ photographs/ Optical Coherence Tomography?)
- **Question ten, part two:** were any other professionals involved in the process? (Prompt: nurse/consultant)
- **Question ten, part three:** Where did the consultation take place? (Prompt: clinic/ hospital/mobile clinic)
- **Question eleven, part one:** were they given a diagnosis then – yes or no?
- **Question eleven, part two:** if not, how many additional days did they have to wait?

Section three: strengths and weaknesses up to diagnosis

Thinking about the process leading up to and including the diagnosis can you answer these questions?

- **Question twelve:** how did you feel about the diagnosis process? (Prompt: were they supported through the process)?
- **Question thirteen:** how well informed did they feel about what was going on? Very well, quite well, not particularly well or not at well at all
- **Question fourteen:** what were the things you felt they were not informed about?
- **Question fifteen, part one:** at the point of diagnosis, did the doctor give them a choice about the treatment options – yes or no?
- **Question fifteen, part two:** were these choices explained clearly? (Prompt: what was the process; did they show them written information etc?)
- **Question sixteen:** was the quality of the care was very good, quite good, average, not very good or not good at all?
- **Question seventeen:** what could have been improved? (Prompt: support, diagnosis, medical training)
- **Question eighteen:** thinking about the whole diagnosis process from start to finish did they feel it was very fast, quite fast, neither, fast nor slow, quite slow or very slow?
- **Question nineteen:** what things could have been improved to speed up the time taken?

Section four: treatment phase

This section is about the treatment or treatments they received after diagnosis

- **Question twenty, part one:** what treatment or treatments were they offered when they were diagnosed?
- **Question twenty, part two:** how soon after they were diagnosed did they begin their first treatment to the nearest day?
- **Question twenty, part three:** were they offered any other treatments at a later date?
- **Question twenty one, part one:** do you feel that treatment “x” was very successful, quite successful, neither, not really successful or not at all successful?
- **Question twenty two:** how frequently have they been given this treatment?
- **Question twenty three:** (if relevant) who administers the injections?
- **Question twenty four, part one:** over what period did this treatment last?
- **Question twenty four, part two:** are they still receiving this treatment?
- **Question twenty four, part three:** what was their overall experience of the treatment process? (Prompt: on the process, the appointments system, the clinician involvement).
- **Question twenty four, part four:** where did the treatment take place?
- **Question twenty five, part one:** along with this treatment, did they have regular follow up appointments?
- **Question twenty five, part two:** what took place at these appointments?
- **Question twenty five, part three:** who were they with, what was their position, was it the same person?
- **Question twenty five, part four:** were there any problems and could anything have been improved?

Note: repeat relevant parts of questions 18–25 for each treatment

Section five: strengths and weaknesses of treatment

During the treatment phase can you tell us about your views on the following?

- **Question twenty six:** how well informed did (do) they feel about what was (is) going on – very well, quite well, not particularly well or not at all well?
- **Question twenty seven:** what were the things they were not informed about?

- **Question twenty eight:** did (do) you feel that the quality of care through the treatment was (is) – very good, good, OK, not very good or not good at all?
- **Question twenty nine, part one:** were appointments ever postponed or cancelled? No never, once, twice, three times or more than three times
- **Question twenty nine, part two:** do you know why these were postponed or cancelled?
- **Question thirty:** what (can) could have been improved?

Section six: adaptations, support and lifestyle

- **Question thirty one:** please tell us about how wet AMD has affected their life?
- **Question thirty two:** what adaptations have they had to make?
- **Question thirty three:** have they had any additional support (such as counselling, social services, rehabilitation or low vision services)? Please tell us about these?
- **Question thirty four:** what parts of this support have worked and which need improvement? What has been your role as a carer?
- **Question thirty five:** have you felt informed about where to get help?

Healthcare professional interview script

Section one: the patient pathway

- **Question one:** what is your role?
- **Question two:** what are the different entry points into the service?
- **Question three:** what typically is a patient's first point of contact when they suspect there is something wrong?
- **Question four:** how long does it normally take them to get a first appointment?
- **Question five:** how long does it normally take from seeing the first professional to them getting a diagnosis and what is normally the time from diagnosis to treatment? How variable is this time? Is a maximum time stipulated? Is it different for different pathways? What are the bottlenecks?
- **Question six:** can you describe the pathways to us? (Prompt: for detail on the diagnosis and treatment phase)
- **Question seven:** which clinicians are involved in the pathway, and at which point?
- **Question eight:** please tell us about your role in the pathway?
- **Question nine:** where do the various parts of the process take place?
- **Question ten:** do you have a visual representation of the pathway you can give to us?

Section two: up to diagnosis

- **Question eleven:** how well informed do you feel patients are about what is going on – very well, quite well, not particularly well, or not at all?
- **Question twelve:** is the quality of care very good, quite good, average, not very good or not good at all?
- **Question thirteen:** what are the areas that most need improvement? (Prompt: support, diagnosis, medical training)?

Section three: the treatment phase

- **Question fourteen:** what treatments are available? Why have you made the decision to offer these treatments?
- **Question fifteen:** are patients given a choice of treatments?
- **Question sixteen:** with injections what is the normal time gap between them? If more than a month for Lucentis, what are the reasons for this? How even are the follow-up appointment and how does the appointment system work?

- **Question seventeen:** who administers injections?
- **Question eighteen:** how well informed did (do) you think patients feel about what is going on – very well, quite well, not particularly well, or not at all well?
- **Question nineteen:** the quality of the treatment is very good, good, OK, not very good or not good at all?
- **Question twenty:** on average would you say appointments are postponed – never, once, twice, three times, or more than three times?
- **Question twenty one:** what in the treatment phase needs to be improved? (Prompt: support, time, training, information)

Section four: awareness and additional support

- **Question twenty two:** how do most people get to know about the condition?
- **Question twenty three:** are there any local awareness raising campaigns on wet AMD?
- **Question twenty four:** what additional support such as counselling, social services, rehabilitation or low vision services is provided to patients?
- **Question twenty five:** what parts of this support work well and which need improvement?
- **Question twenty six:** how well informed do you think patients are about additional support available?

Section five: commissioning and evaluation of services

- **Question twenty seven:** are you involved in commissioning decisions?
- **Question twenty eight:** how are your costs controlled?
- **Question twenty nine:** how can the commissioning of services be improved?
- **Question thirty:** how is your service monitored and evaluated?
- **Question thirty one:** is there anything else I have not covered that might be useful for the RNIB to know when trying to promote better services for wet AMD patient?

Commissioner interview script

- **Question one:** what is your role?
- **Question two:** who else is involved in eye care commissioning decisions?
- **Question three:** what are your criteria for commissioning wet AMD services?
- **Question four, part one:** what are the main challenges in commissioning this service?
- **Question four, part two:** where are the bottlenecks?
- **Question four, part three:** how does the referral system work?
- **Question five:** what analysis do you normally have to make decisions on? (Prompt: hard and soft data?)
- **Question six, part one:** how often do you make or review commissioning decisions?
- **Question six, part two:** how does this process work?
- **Question seven, part one:** how do you monitor and evaluate the service?
- **Question seven, part two:** how is the patient view incorporated into this?
- **Question eight:** how do you prioritise within the budget and between budgets?
- **Question nine:** can you describe the pathway or pathways? Do you have a visual presentation you could give to us? Is it the case that you can say how long it took for someone to get their injections and the gaps between them?
- **Question ten, part one:** how do you prioritise patients financially across the year?
- **Question ten, part two:** what proportion of patients come via GPs, optometrists and other routes and are there any differences to their clinical outcomes? Have you done any specific work to improve this?
- **Question ten, part three:** how long does it typically take to get a first appointment?
- **Question ten, part four:** what is the typical interval between intravitreal injections?
- **Question eleven:** in the diagnosis phase what are the key things that need to be change/be improved?
- **Question twelve:** for the treatment phase what are the key things that need to change/be improved? Who administers injections and is it something you are trying to nudge in a certain direction?
- **Question thirteen:** for after care and additional support (Prompt: relationship with social care), what additional support such as counselling, social services, rehabilitation or low vision services is provided to patients?

- **Question fourteen:** for after care what are the key things that need to change or be improved?
- **Question fifteen:** which of the above should be the priority?
- **Question sixteen:** are there any service reconfigurations or changes in clinical practice that you have not already mentioned that might improve things? Are there any examples of best practice that you could point us to?
- **Question seventeen:** are there any future medical or other developments that will impact on the way you commission services?
- **Question eighteen:** are there any local wet AMD awareness raising campaigns?
- **Question nineteen:** how are commissioning decisions made? How will the move to Clinical Commissioning group commissioning impact on the way services are commissioned? What about getting the patient perspective?
- **Question twenty:** is there anything else I have not covered that might be useful for the RNIB to know when trying to promote better services for wet AMD patient?

Commissioner survey

- **Question one:** do you (or another NHS body covering your area) have someone in post know who is responsible for commissioning eye care (retinal/ophthalmic)?
- **Question two:** if the answer is yes, who are they employed by?
- **Question three:** how long have they been in post?
- **Question four:** are they specifically responsible for commissioning wet AMD services – yes or no?
- **Question five:** what other services are they responsible for?
- **Question six:** who else is involved in commissioning decisions about wet AMD?
- **Question seven:** do you use outside additional expertise for commissioning wet AMD services – yes or no?
- **Question eight:** if the answer to seven is yes, please explain?
- **Question nine:** is your current wet AMD service able to comply with Royal College guidelines on diagnosis timeframes (two weeks to treatment) for at least 90 per cent of patients – yes, no or don't know?
- **Question ten:** is your wet AMD service able to meet NICE guidelines on monthly monitoring and injections for those who need them? Yes, no, don't know or not using Lucentis?
- **Question eleven:** what is your expectation of demand for wet AMD services over the next few years? Fall a lot, fall slightly, stay the same, rise slightly, rise a lot or don't know?
- **Question twelve:** does the analysis on which you make commissioning decisions include the perspective of patients – yes, no or don't know?
- **Question thirteen:** does the board receive regular reports on eye care performance and eye health issues – yes, no or don't know?
- **Question fourteen:** How often do you review commissioning decisions?
- **Question fifteen:** will the move to CCGs from PCTs: make it easier to commission wet AMD services; make it harder to commission wet AMD services; or make no difference
- **Question sixteen:** is there anything else it might be useful for the RNIB to know when trying to promote better services for wet AMD patients?

RNIB
105 Judd Street
London
WC1H 9NE
rnib.org.uk

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