Managing wet AMD: aiming to optimise the patient journey

Jane's journey – a hypothetical Costed Integrated Patient Scenario

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Contents

Executive summary

This Cost Integrated Patient Scenario (CIPS) analysis uses suboptimal and optimal pathways – developed by an expert clinically-led consensus group for a fictional patient, Jane – to compare the differences in care that a patient with wet age-related macular degeneration (AMD) can receive and the effect this can have on patient experience and outcomes, as well as estimated system costs.

The impact on the patient is the most notable difference between the pathways.

- **In the suboptimal pathway, Jane loses sight in one eye, requires support from a carer, and experiences greatly reduced quality of life and unnecessary distress.**
- **In the optimal pathway, Jane retains her vision and maintains a mostly independent life, while at the same time generating significant estimated savings of £13,969* for the NHS and the taxpayer in the process.**

Key learnings

- A good-quality urgent referral with scans and background information allows hospital eye services to make an early diagnosis and arrange a prompt first appointment.
- Providing verbal and written patient information at all stages in the treatment pathway reassures patients and ensures they can have informed discussions.
- Signposting to the Macular Society allows patients to access patient-specific information and benefit from peer support.
- Good communication between healthcare professionals and patients results in a more positive care experience, ensuring they have better understanding of their condition and feel involved in their care process.
- A one-stop diagnosis and injection clinic can confirm diagnosis promptly, facilitate discussion about treatment options, offer patients their first injection in the first hospital appointment, and allow monitoring during subsequent injection appointments.
- Ensuring all treatment options are available allows consultants to personalise treatment by selecting the product most appropriate to a patient's individual circumstances.
- Availability of durable treatments results in fewer injections, fewer consultations and procedures.
- An efficient, flexible and resilient service ensures that recommended targets – such as starting treatment within 14 days of referral and completing the loading phase of intravitreal injections within 10 weeks – can be achieved, appointments can be rescheduled quickly when needed, and patients receive injections on schedule, as often as possible.
- Offering patients a choice of time and location for appointments increases the likelihood that patients will be able to attend as scheduled.
- Improved outcomes and patient experience reduce costs from complications such as depression, anxiety and sight-related falls.
- Offering virtual review and patient-initiated follow-up once a patient's disease is stabilised reduces the burden on hospital eye services for face-to-face appointments and ensures patients have easy access to the service if their vision deteriorates.

The scenarios in this report have been developed based on the opinions of experts in this specialist field with analysis of costings undertaken by the HSJ Advisory team.
*Full details of financial calculations are available on p29-31.

Forewords

Dr Elizabeth Wilkinson,
Consultant Medical Ophthalmologist,
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Macular disease is the leading cause of sight loss in the UK and developed world.[a] Nearly 1.5 million people in the UK have macular disease, with age-related macular degeneration (AMD) the most common condition.[b] Neovascular (wet) AMD is a sight-threatening condition, which if left undiagnosed and untreated, can lead to rapid and complete central vision loss over a few months, and 26,000 new cases of wet AMD are diagnosed in the UK each year.[c] Early diagnosis and timely escalation onto appropriate treatment pathways are critical to ensuring the best possible outcomes for patients, where delays in treatment can cause rapid deterioration of eyesight.

This document sets out the effects, both in human and economic terms of a current average standard of care and recommended best practice, using established methodology with an expert clinically-led consensus group.

Outlined here, is a story of our fictional patient, Jane, who experiences different outcomes on a suboptimal and optimal pathway of care as a result of her treatment and experience of wet AMD. Jane's suboptimal journey is characterised by challenges at every step of the way from her diagnosis to treatment initiation and ongoing management. She enters a commonly encountered pathway in the UK and worldwide, becoming stuck in a cycle of monthly treatment injections, with frequent delays and cancellations which severely compromise effective treatment and results in gradual and then sudden vision deterioration.

Conversely, an optimal pathway puts the patient at the heart of their own journey. Underpinning optimal care is timely diagnosis and initiation of effective treatment, which is well managed effectively through the treatment course, with patients well informed at each step of their journey.

The current shift within the healthcare landscape toward cost-saving treatment options, while understandable in the context of financial pressures, must be approached with appropriate clinical caution. Where these lower cost treatment options fail to alleviate system burden or compromise long-term patient outcomes, they may ultimately prove more costly and less effective. Moreover, there is a risk that patients may not be offered the most clinically appropriate or beneficial care, undermining the goal of delivering true value for both patients and the NHS.

I thank all involved for their invaluable perspectives and I hope that this document, co-produced by medical retina clinical specialists, service managers, payors and a patient organisation, can contribute to supporting improvements in the diagnosis, treatment and management of patients with this debilitating disease, which will lead to improved patient outcomes, and support the NHS in delivering patient-centric services more efficiently.

a. Macular Society. *What is macular disease.* Available at: https://www.macularsociety.org/macular-disease/ (accessed April 2025).
b. Macular Society. *Macular conditions.* Available at: https://www.macularsociety.org/macular-disease/macular-conditions/ (accessed April 2025).
c. Getting It Right First Time (GIRFT). *Ophthalmology: GIRFT Programme national specialty report.* 2019. Available at: https://gettingitrightfirsttime.co.uk/wp-content/uploads/2019/12/OphthalmologyReportGIRFT19P-FINAL.pdf (accessed April 2025).

Jane's story, as outlined in the Costed Integrated Patient Scenario, is similar to the story of many people with wet AMD, who the Macular Society speaks to each and every day. At the Macular Society, we regularly hear about experiences just like the optimal and suboptimal pathways outlined in this report, and highlighted here are those small changes in care that over time can lead to vastly different outcomes for patients.

Sarah Clinton
Patient Information Officer,
Macular Society

The difference between the two pathways highlights the disparity in available care, support and patient information, and the impact this can have on patient outcomes. In the suboptimal pathway, our fictional patient, Jane, is not given sufficient information and doesn't know how to access available support. She is left isolated, confused and anxious about her condition. The suboptimal journey highlights many small instances where patients such as Jane are able to slip through the cracks within the system, missing opportunities to access the help and support they need. A survey of members of the Macular Society found that nearly six out of 10 have experienced a delay while waiting for an NHS appointment or treatment and that 30% feel abandoned by the NHS or authorities.[d]

However, the optimal pathway, as determined by this consensus group, highlights differences that extend beyond drug treatment. Our fictional patient is able to access the correct patient information at the right time and is efficiently signposted to local low vision assessment services and peer support. This all allows her to better understand her wet AMD, meet others who are going through similar experiences, and feel in control of her own patient journey.

Through an optimal pathway, Jane is able to maintain vision and independence, improving her social, mental and physical wellbeing. We hope that this project highlights the importance of patients with wet AMD being involved in their own treatment journeys, receiving the right information at the right time, and being signposted to appropriate patient support and communication at each step during their treatment pathways.

d. Association of Optometrists. *NHS patient backlogs are leading to life-changing sight loss.* Available at https://www.aop.org.uk/our-voice/media-centre/press-releases/2023/03/21/nhs-patient-backlogs-are-leading-to-life-changing-sight-loss (accessed April 2025).

Introduction

The retina is a layer of neurosensory tissue in the eye, which converts light into neural signals that the brain interprets as images (Figure 1).[1] The macula is a tiny part of the retina – the size of a grain of rice – at the back of the eye.[1,2] It is responsible for central vision and fine detail and also contributes to colour vision.[1,2]

Macular disease is the biggest cause of sight loss in the UK and developed world.[2] If the macula becomes damaged, the central field of vision may become blurred or distorted. Gradually, the photo receptors in the macular die and central vision can be lost.[2] Nearly 1.5 million people in the UK have macular disease, with age-related macular degeneration the most common type and also the most common cause of certification for vision impairment.[2,4,5]

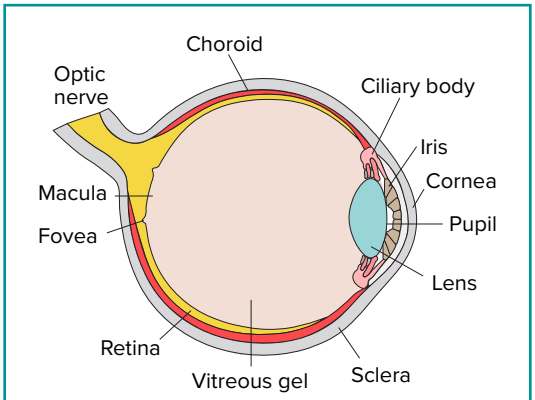


Figure 1. Anatomy of the eye.[3]

About AMD

Age-related macular degeneration (AMD) is defined as age-related changes, without any other obvious precipitating cause, which occur in the macula in people aged ≥50 years:[1,5,6]

- collections of lipids and other materials, called drusen, that accumulate beneath the retinal pigment epithelium (RPE) and within Bruch's membrane
- areas of hypopigmentation or hyperpigmentation abnormalities in the RPE
- sharply demarcated areas of partial or complete depigmentation of the RPE – described as geographic atrophy – that develop due to breakdown of light-sensitive cells in the macula; these can enlarge over time and may or may not involve the fovea, a small, central pit in the macula, responsible for sharp central vision.
- development of new blood vessels in the choroid – called choroidal neovascularisation – that, unlike normal vessels, easily bleed or leak blood constituents, resulting in distortion and scarring of the retina.

What causes AMD is unknown, but numerous risk factors have been identified (Box 1).[1,6]

Box 1. Risk factors for AMD.[1,6]

- Older age
- High cholesterol
- Micronutrient deficiency
- Smoking
- Family history
- Hypertension
- Cardiovascular disease
- Exposure to visible light
- Genetic factors

In the UK, AMD affects an estimated 700,000 people and is the primary cause of sight impairment certification.[7,8] The prevalence of AMD increases with age, affecting one in 200 people aged 60 years and increasing to one in five people aged 90 years.[7] The prevalence has also increased over time as our population ages – from about 450,000 in 2013 to about 700,000 in 2025 – and is estimated to exceed 1.2 million by 2050.[7,9,10] Early AMD is more common among individuals of European ancestry compared to Asians, and AMD of any stage is less common in individuals of African origin.[1,6]

About 26,000 new cases of wet AMD are diagnosed in the UK each year.[9] It affects both men and women, usually those aged >50 years, with the risk increasing significantly with age.[9]

Symptoms of AMD

AMD is a painless condition that generally leads to gradual impairment of vision but can also cause rapid reduction in vision.[5] Symptoms include:[1,6]

- distortion of vision, where straight lines appear crooked or wavy
- painless loss, or blurring, of central or near-central vision
- black or grey patch affecting the central field of vision (scotoma)
- difficulty reading, driving or seeing fine detail (such as facial features)
- flickering or flashing lights (photopsia)
- difficulty adjusting from bright to dim lighting
- visual hallucinations (associated with severe visual loss)
- normal or reduced visual acuity.

Complications of AMD include visual impairment and blindness, visual hallucinations, depression, falls and fractures, and reduced quality of life.[1,6]

AMD can make everyday activities such as driving, reading and recognising faces difficult.[6]

Types of AMD

AMD may be characterised as early, intermediate, and late or advanced.[3]

- Early and intermediate AMD may have no symptoms or vision loss.[3,6] The condition is often picked up during routine eye examinations due to the presence of drusen in the macular area.[3] There is a low, medium or high risk of progression.[6]
- Late/advanced AMD primarily affects central vision and usually affects both eyes, although one may be affected before the other.[3] An unaffected eye may compensate for the affected eye, so vision impairment is not noticed in the early stages.[3]

The two main types of late or advanced AMD are late dry and wet active,[1,3,6] which relate to observations at the back of the eye when the eye is examined, not whether the patient feels that their eye is dry or watery.[3]

- Late dry AMD, also known as geographic atrophy, is characterised by gradual loss of central vision as retinal cells degenerate to the point where they no longer work and are not replaced.[3,6] It is the most common type of AMD and progresses slowly over years.[3,6] Some cases of dry AMD progress to wet AMD.[3]

- Wet AMD, also known as exudative or neovascular AMD,[3] affects 10–15% of people with late AMD and often progresses from dry AMD.[1,3] When photoreceptor cells of the macula stop working correctly, new blood vessels grow from the choroid, and it is this choroidal neovascularisation (CNV) that differentiates wet AMD from dry AMD.[1,3] The presence of new blood vessels causes swelling and bleeding underneath the macula, further damaging the macula and leading to scarring.[1,3] Wet AMD develops very quickly, causing serious changes to central vision over months, weeks or even days.[3,6] Various factors contribute to development of CNV and vision loss in patients with wet AMD (Box 2).[1,6]

Box 2. Factors contributing to development of choroidal neovascularisation and vision loss.[1]

- Accumulation of vascular epithelial growth factor (VEGF)
- Growth of new blood vessels with proliferation of fibrous tissue
- Leakage of fluid, proteins, and lipids from the new vessels
- Haemorrhage from fragile new vessels
- Retinal cell death with scar formation, leading to permanent vision loss

Diagnosis of AMD

On physical examination, patients often show decreased best-corrected visual acuity.[1] An Amsler grid test may reveal areas of central or paracentral scotoma or visual distortion.[1]

Accurate diagnosis relies on ocular imaging techniques that assess retinal and choroidal changes (Box 3).[1,6] The main methods are:

- optical coherence tomography (OCT) – a non-invasive imaging method that captures detailed images of the retina and surrounding structures and features of AMD[1,5,6]
- OCT angiography (OCT-A) – a newer technology that creates images of retinal circulation.[1] It may facilitate earlier diagnosis of CNV, potentially identifying lesions before they are visible on conventional OCT or fluorescein angiography.

Box 3. Imaging techniques used to diagnose AMD.[1,6,9]

- Slit-lamp biomicroscopy
- Colour fundus photography
- Optical coherence tomography (OCT)
- Fundus fluorescein angiography (FFA)
- Indocyanine green angiography (ICGA)
- OCT angiography (OCT-A)

Undiagnosed and untreated wet AMD can lead to rapid complete central vision loss in a couple of months.[9]

Treatment of AMD

Vascular epithelial growth factor (VEGF) is a pro-angiogenic growth factor that stimulates vascular permeability and has a major role in the onset and progression of conditions such as AMD, some diabetes-associated ophthalmic complications, and retinal vein occlusion.[1,6,11-14] The mainstay of therapy for wet AMD is anti-VEGF treatment.

Anti-VEGF drugs reduce new blood vessel growth and swelling and so can stabilise abnormal blood vessel growth and swelling under the macula.[1,6,11–14] Anti-VEGF drugs can prevent visual loss and may also improve vision in some cases,[1] but they need to be started promptly before new blood vessels and swelling cause too much damage to the macula.[14] The Royal College of Ophthalmologists' National Ophthalmology Database (NOD) Audit on AMD showed that at the end of the first year of treatment with anti-VEGF drugs:[8]

- the proportion of eyes with "good" visual acuity increased to 43%
- the proportion of eyes with "poor" visual acuity decreased from 18% to 15%
- most eyes with "good" vision at the start of treatment retained this level of vision
- the proportion of eyes with significant visual loss decreased from 50% to 10% when compared to the natural history of untreated eyes
- only about 65% of patients received their loading dose of anti-VEGF treatment within the recommended 10-week period. Delivery of this key part of the care pathway was also worse for patients who were older and/or who started treatment in both eyes.

All anti-VEGF injections are given directly into the vitreous body – the jelly-like substance that fills the eye – typically with an initial loading phase of monthly dosing followed by maintenance treatment.[1,2] First-generation anti-VEGF inhibitors have an average durability of typically every 1–2 months, thus requiring frequent injections and clinic visits for maintenance.[1,15,16] This poses a considerable burden for patients and can lead to reduced adherence, which is a major reason for treatment failure.[1,15,16] Second-generation agents have extended durability with longer treatment intervals, which reduces the frequency of injections.[1,15,16] Methods such as 'treat and extend', use flexible dosing regimens, where the patient is monitored and injection intervals are gradually extended as long as disease activity is stable and the macula is dry.[1] When following this protocol, the second generation agents result in fewer injections per year, reducing the treatment burden for many patients.[15] In some patients, treatment can be stopped when the macula is persistently dry, with regular evaluations to monitor for disease activity.[1]

Some patients do not respond or respond suboptimally to one drug but achieve desired outcomes with another. Different treatment options being available provides ophthalmologists the flexibility to prescribe treatment as clinically appropriate to ensure the best care for their patients.[9]

> In the absence of anti-VEGF therapy, around 79–90% of affected eyes eventually become legally blind due to complications from neovascularisation.[1]

> The duration of drying effect of the first generation anti-VEGF drugs is not as effective as the second-generation anti-VEGF treatment options, so more patients need to be monitored at shorter intervals and injected.[17] The overall cost-savings of using first generation anti-VEGFs are unlikely to be significant, especially when about 70% of patients receiving durable agents can achieve 12-weekly or longer intervals between injections after the loading phase in clinical trial settings.[17]

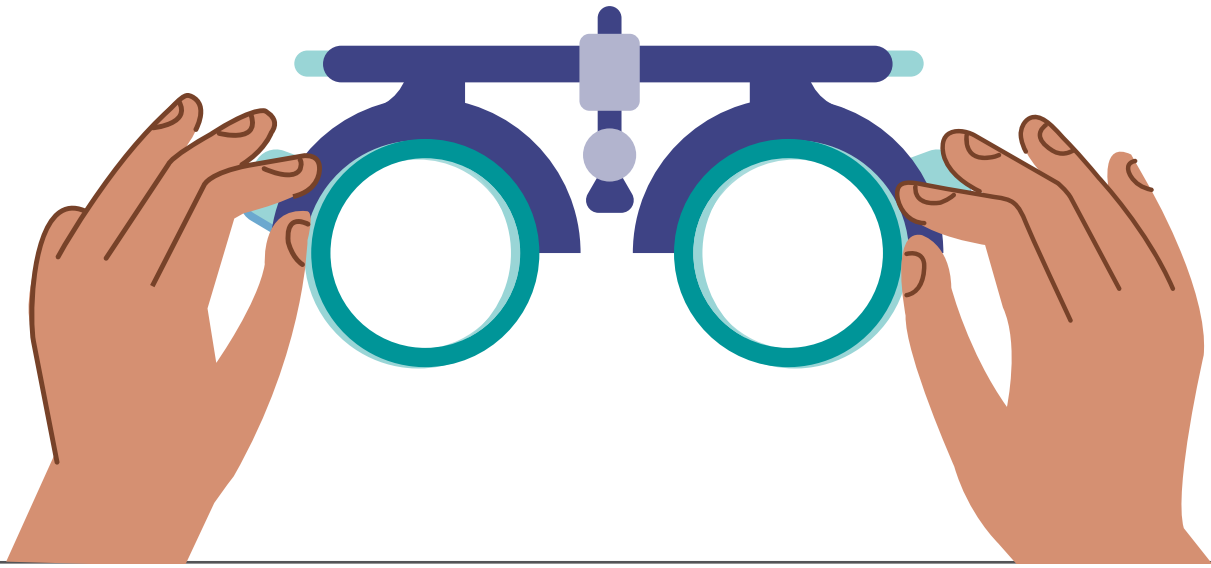
Analysis style

NHS RightCare has developed a series of long-term conditions scenarios using a style of analysis where suboptimal and optimal case studies of a fictitious, but realistic, patient are compared and contrasted. The intention is to highlight potential improvement opportunities.

The RightCare work is powerful – and often moving – and as such the goal is to inspire more stakeholders to take note and take action towards positive change.

The aim of the Macular Society, like NHS RightCare, is to raise awareness through supporting local health economies – including clinical, commissioning and finance colleagues – to think strategically about designing optimal care for people, in this case for those at risk of vision loss.

This scenario has been developed with experts in this specialist field, including ophthalmologists, service managers, payors and a patient organisation, and provides prompts for commissioners to consider when evaluating their local health economy requirements.



The story of Jane's experience of a wet AMD care pathway, and how it could be so much better

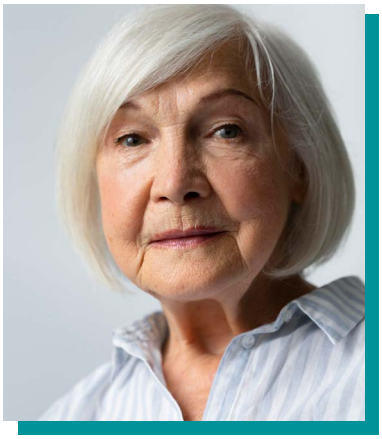
In this scenario using a fictional patient, Jane, we examine the patient journey for wet AMD, comparing a suboptimal clinical scenario, bordering on worst-case, against an ideal pathway. At each stage, we have modelled the costs of care, not only financially to the local health economy, but also the cost impact on the patient and her family's experience.

This scenario has been produced in partnership with clinical and patient stakeholders using the NHS RightCare methodology. The aim is to help clinicians and commissioners improve value and outcomes for this patient group.

This document is intended to help commissioners and providers understand the implications, both in terms of quality of life and costs, of shifting the care pathway from suboptimal to optimal for relevant patients. While the described suboptimal pathway reflects the expert group's view of where many organisations currently operate, shifting towards the optimal journey outlined here can enhance patient outcomes and experience, demonstrating how such changes support clinicians and commissioners in improving the value and effectiveness of the care pathway.

Introducing Jane

Our fictional patient, Jane Smith, is an 80-year-old widow, who retired from work as a schoolteacher and lives independently. Her two adult children live in different cities, visiting occasionally but in regular contact by phone.



Jane has always been a vibrant and self-sufficient individual. After retiring from her rewarding teaching career, she has devoted her time to gardening, reading novels and volunteering at a local library. A firm believer in staying active, Jane also participates in light exercise and enjoys walks in her neighbourhood.

Despite her positive outlook, Jane has had some issues with her health over the years. She has hypertension and mild hyperlipidaemia, which are controlled with medication. She was diagnosed with dry AMD a decade ago.

Although Jane tries to avoid thinking too much about her early dry AMD, her family history of macular degeneration lingers as a concern. Her mother, who died aged 77 years, had sight issues due to AMD, but Jane is unsure of which type. She has noticed a sudden change in her own vision recently – the straight lines in her garden fence seem wavy, and she struggles with tasks that once came effortlessly, such as reading fine print in her novels and recognising familiar faces in photographs. Jane realises that she needs to see an optometrist, and this is where her story begins to diverge in the suboptimal and optimal pathways that follow.

Meet Jane Smith

- 80 years
- Female
- Caucasian
- Widowed for over a decade

Medical history

- Long-standing early dry AMD diagnosed 10 years ago
- Hypertension (managed with medication)
- Mild hyperlipidaemia (managed with medication)
- Family history of AMD (mother)

Social history

- Retired schoolteacher
- Living independently
- Drives her own vehicle
- Two adult children
- Non-smoker (quit 20 years ago after a 30 pack-year history)
- Rare alcohol consumption
- Past exposure to sunlight during gardening without consistent use of sunglasses

Jane's optometrist appointment and referral

Suboptimal pathway

Jane was given very little information when she was initially diagnosed with early dry AMD 10 years ago. Consequently, she does not really understand what dry AMD is, thinking it means her eyes are dry, she does not realise that it can progress to wet AMD, and she is unaware of the symptoms and signs that wet AMD is developing, thinking that wet means her eyes will feel watery. However, because of the dry AMD diagnosis, she is a regular visitor to the optometrist and attends her next routine appointment, where she pays to have an OCT scan.

Without clear explanations, patients often misunderstand the terms 'dry AMD' and 'wet AMD', thinking that the former means their eyes just feel dry, while the latter means their eyes feel watery. It is important to explain what these two terms mean when they are diagnosed and the differences in prognosis for the two conditions, highlighting the signs that wet AMD is developing, emphasising the need to see an optometrist quickly rather than waiting for a routine appointment, and providing written information and signpost them to helpful resources and support.

The optometrist appointment and referral process

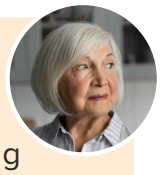
On reviewing the OCT scan, the optometrist believes Jane could have wet AMD in her left eye and emails the eye services at the hospital on the day of her appointment as a routine referral. No image of the OCT is attached to the referral and little information is provided, just noting that the optometrist thinks Jane has wet AMD.

For patients with suspected wet AMD, the National Institute for Health and Care Excellence (NICE) recommends an urgent referral to a macular service whether or not they report any visual impairment.[5] The College of Optometrists recommends an urgent/priority – with a suggested telephone call to the eye department for triage – in line with local protocol.[18]

Patients with suspected wet AMD must not be referred via the GP, as this creates a significant delay in them being seen and may result in the serious consequence of permanent sight loss.[19]

Jane's referral enters a queue at the hospital eye services for the wet AMD clinic and the referral is triaged the following week without the OCT scan. Jane cannot be directed to the wet AMD patient decision support tool on the NHS app because her referral quality is too poor to diagnose wet AMD. Currently, 60–74% of referred patients do not have wet AMD.[20, 21]

> A clearly worded referral should include relevant details from the eye examination, the reason for the referral (with images where appropriate), details of discussions with the patient and with the practitioner to whom the referral is being made, and the level of urgency.[22]



Jane's experience

The optometrist gives only a brief verbal explanation to Jane about the referral, saying that they believe 'she has a wet macula' and that it is possible that Jane could be going blind. Jane is left anxious and confused, thinking she has a watery eye. The wait between her optometrist appointment and the first hospital appointment is a stressful time, and she remains anxious and confused waiting for an update at home. A week later, she receives a phone call from the hospital inviting her to an appointment in two weeks. Jane then receives a letter in the post confirming her appointment at the hospital.

> When referring a patient, they must be given a written statement of the reasons for referral, immediately following the sight test; if the referral letter cannot be written immediately, the reason for referral should be written elsewhere – for example on the patient's prescription. The referrer must ensure that the patient understands the urgency of the referral and tell the patient when they should expect to hear about their referral and what to do if they do not hear within that timescale. The patient should be told what to do if their symptoms get worse before they are seen. The patient should be given copies of any correspondence relating to them so that they are clear about their condition and the care they are receiving. Copies of correspondence and any relevant supporting information should be provided in an accessible format.[22]

> The patient should be advised that if there is a delay of more than one week in being seen by an optometrist or ophthalmologist, or symptoms become worse while they are waiting to be seen, they should attend eye casualty, if available, as soon as possible, or seek other immediate medical attention to expedite urgent specialist assessment.[6]

Optimal pathway

Following Jane's diagnosis of early dry AMD and information provided at the time, she is aware that her dry AMD can develop into wet AMD and knows the warning signs. This has been further supported by public health campaigns on eye health and awareness of central vision loss or distortion. Jane occasionally checks an Amsler chart on her mobile phone and begins to notice subtle changes, with some lines appearing blurry to her. With the other changes she's noticed in her vision in her daily life, she realises she needs to arrange an early consultation rather than waiting for her next routine appointment. Because of the AMD diagnosis, Jane pays to have an OCT scan.

The optometrist appointment and referral process

Based on the OCT scan, the optometrist suspects wet AMD in Jane's left eye and initiates a same-day referral via a fast-track electronic Eye Referral Service (eERS). The referral includes clinical findings, vision, new distortion, and the OCT image. The optometrist also notes in the referral that Jane has hypertension and mild hyperlipidaemia managed by medication. The optometrist is aware of the importance of providing the highest quality referral possible to give the hospital sufficient information to triage the referral to ensure patients are given a face-to-face consultation when needed.

The hospital reviews and triages Jane's referral on the same day. The referral from the optometrist includes vision, a reviewable OCT scan of the correct part of the eye, Jane's medical history and volumetric OCT. The scan quality from the optometrist is good, so a senior clinician is able to diagnose Jane with wet AMD from the referral. The senior clinician calls Jane within 48 hours of the optometrist's referral, informs her of the diagnosis, and invites her to a face-to-face examination at the hospital's consultant-led, one-stop diagnosis and intravitreal injection clinic. The clinician gives Jane advice using shared decision making, and Jane is identified as a patient potentially requiring additional support. The clinician directs Jane to the wet AMD patient decision support tool on the NHS app and information from the Macular Society, so she arrives at hospital more informed.

Jane's experience

At the optometrist appointment, Jane's knowledge of her early dry AMD and potential progression to wet AMD allows her to have an informed discussion with the optometrist. The optometrist clearly explains the reason for Jane's referral as a precautionary measure, and Jane is not given too much information about wet AMD so as not to overburden her or create anxiety, as 60–74% of people referred to hospital eye services do not have wet AMD.[20,21] Jane feels at ease following the appointment and continues in her daily life.

Jane receives a phone call from the consultant at the hospital, who explains that she has been diagnosed with wet AMD. The consultant talks Jane through what this means and confirms that an urgent referral appointment has been arranged for her at the hospital within two weeks. The consultant explains to Jane that some tests will be repeated at the hospital and that Jane will likely require anti-VEGF injections. The clinician also directs Jane to the wet AMD patient decision support tool on the NHS app, allowing her to read through this in her own time ahead of the hospital appointment. Jane also receives a letter a few days later confirming her appointment at the hospital eye service the following week.

Jane's first hospital appointment

Suboptimal pathway

First hospital appointment

Three weeks after Jane was referred by the optometrist, she attends her first hospital appointment. She is taken to her first ophthalmology appointment by a friend, as she has been advised not to drive herself as she will be having both eyes examined and lives in a rural area with limited public transport. During this appointment, a repeat OCT test is performed, and the clinician diagnoses wet AMD based on this test. Baseline visual acuity at diagnosis is also measured: 6/12 in the left eye with wet AMD and 6/9 in the right eye.

> NICE recommends that OCT should be offered to people with suspected wet AMD.[6]

The ophthalmologist discusses treatment options with Jane. A treatment plan of anti-VEGF injections is selected, and Jane is consented. She is told she will receive an injection date in a few weeks' time and will be started on a monthly injection plan. The clinician follows local protocol, with limited options of available injections, which does not include social considerations on how difficult it is for a patient to attend regular appointments. Jane is not offered the possibility of different injection locations and is told that the injections will all take place at the hospital.

> It is important to ensure that local pathways for referral, assessment and initial treatment are efficient[23] to avoid delays in starting treatment.

Jane's GP is notified about the diagnosis and treatment plan.

Jane's experience

Jane spends four hours at the hospital having scans and waiting around. She feels overwhelmed from being moved from one area to another and by the amount of information being provided to her at each stage. The ophthalmologist discusses treatment options with Jane, and a treatment plan is selected. Jane is given a lot of verbal information about wet AMD, its treatment and what the injections will mean.

Jane returns home from the hospital following her appointment. She was not given a date for her first injection, being told that her next appointment will be communicated via letter. She struggles to come to terms with her diagnosis and cannot remember getting any information about wet AMD. She feels concerned about the journey ahead, and the lack of information about her next appointment leaves her feeling anxious and uncertain.

Optimal pathway

First hospital appointment

Two weeks after Jane was referred by the optometrist, she attends the hospital's consultant-led one-stop diagnosis and intravitreal injection clinic. She is taken to her first appointment by a friend, as she has been advised not to drive herself as she will be having both eyes examined and lives in a rural area with limited public transport. Tests are repeated at this appointment, beginning with an OCT, which further indicates she has wet AMD. Jane then undergoes OCT-A, as recommended by the Royal College of Ophthalmologists (RCO)[17] – which confirms the diagnosis of wet AMD. Her baseline visual acuity at diagnosis is also measured: 6/12 in the left eye with wet AMD and 6/9 in the right eye.

OCT is the first diagnostic test for patients with AMD and the most sensitive tool to assess response to treatment, including reactivation of wet AMD.[17] When the structural OCT shows features suggestive of wet AMD, evidence of macular neovascularisation on OCT-A is considered adequate evidence to initiate therapy.[17]

OCT-A has become more widely accepted as a rapid, sensitive, and non-invasive imaging test for detection and management of wet AMD,[17] as most hospitals do not have fast access to FFA and this would introduce a further wait of around one week before the diagnosis was confirmed. However, FFA may be used in specific cases where OCT-A does not confirm the presence of neovascularisation.[17]

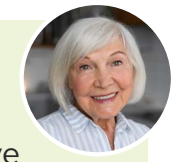
The ophthalmologist discusses treatment options with Jane, and a treatment plan of anti-VEGF injections is selected. The consultant works to the set protocol within the treatment criteria to standardise prescribing, and all appropriate treatment options are available to Jane, including a durable agent. She is consented and has her first injection of a durable anti-VEGF treatment that day, receiving the treatment within 14 days of the primary care referral, as recommended by NICE.[24]

As wet AMD can deteriorate rapidly, any delay to starting treatment may lead to a worsening of outcomes over the long term.[24] Minimising delays in starting treatment increases the chance of preserving vision and so quality of life.[24]

Treatment should be started, when appropriate, within 14 days of referral from primary care so patients have the best possible chance of keeping their sight.[8,24]

While still at the hospital, Jane is given her next two injection dates. She is offered a choice of where to have her injections and chooses a location closer to her home than the hospital. The booking team member writes all of the appointment dates and the treatment type in a booklet that is given to Jane, along with leaflets produced by the Macular Society. Jane's appointment dates are also uploaded to the NHS App, where she can readily access them.

The hospital sends feedback to the optometrist on the quality of the referral, including a copy of the letter, Jane's diagnosis and treatment plan. Jane's GP is also notified about the diagnosis and treatment plan.

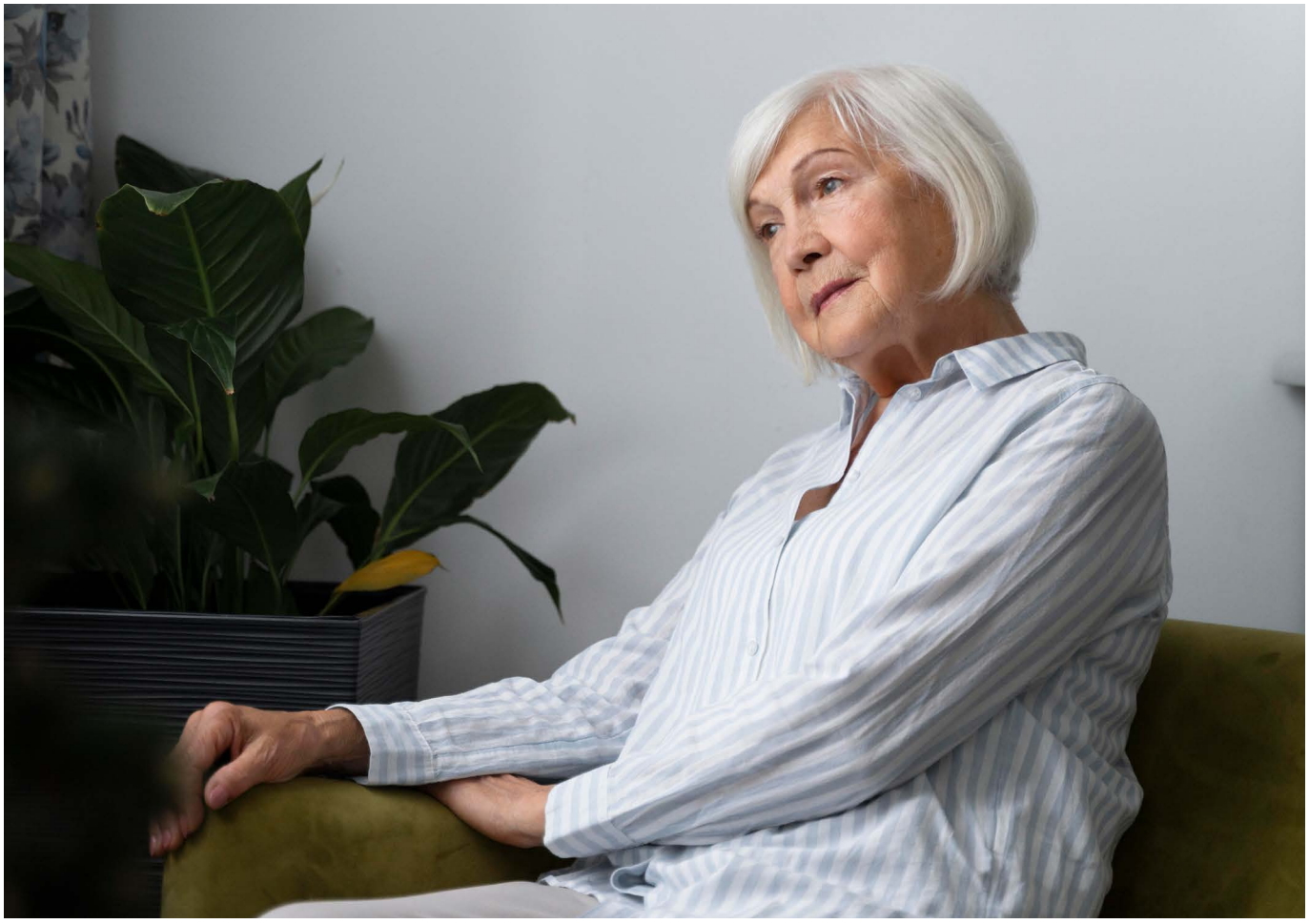


Jane's experience

Jane is grateful for her initial conversation with the senior clinician, who called to give her the diagnosis and provided her with information about what her treatment pathway may look like ahead of her first hospital appointment. She feels like she can have informed conversations at the hospital and is a bit more prepared.

During her appointment, Jane is given clear information on wet AMD by the ophthalmologist – both verbally and through materials. The ophthalmologist provides Jane with a number of Macular Society leaflets and information sheets. She is given time to process the information the consultant has given her, as the visit to the hospital can be an overwhelming time.

After talking with Jane, the hospital desk staff suggest that she contact the Macular Society group for support, which Jane does after returning home, and she is put in contact with patient support groups in her local area. Jane becomes more informed about her condition and what she can expect on the treatment pathway.



Jane's ongoing management and outcomes

Suboptimal pathway

Ongoing treatment

Six weeks after her optometrist referral, Jane receives her first injection of anti-VEGF treatment – later than the 14 days from primary care referral recommended by NICE.[24]

> In the 2025 NOD audit, only 40.3% of eyes with wet AMD received their first anti-VEGF injection within 14 days of primary care referral, 25.0% within 28 days and 34.8% after more than 28 days.[8]

Although Jane is able to attend hospital for her second anti-VEGF injection four weeks later, she is unable to attend her third injection four weeks after that. She contacts the hospital to rearrange, but there is very limited flexibility in the system, and she can only be offered a new appointment in three weeks, thus receiving her third injection 17 weeks after her initial referral. The limited booking process and non-fast-track referral pathway means that Jane does not receive her first three loading injections within the recommended 10-week loading phase.[8]

> The initial loading phase of three-monthly injections should be completed within 10 weeks.[8] In the 2025 NOD audit, only 64.8% of first treated eyes completed the loading phase within the 10 weeks.[8]

Jane attends the appointment for her fourth anti-VEGF injection, as per the monthly schedule, but she begins to struggle with the burden of monthly trips to the hospital for injections, often due to issues around transport. As time progresses, Jane misses more injection appointments, and some are cancelled by the hospital. Continued delays in availability for rescheduled appointments means she does not receive all of her injections as per the monthly schedule.

> Delay to the planned treatment intervals can lead to poor visual acuity outcomes and are a cause of concern to patients. The NICE Quality Standard on Serious Eye Disorders recommends monitoring the proportion of scheduled appointments that are cancelled or delayed by the provider.[8]

There is a lack of communication between Jane and her clinicians, and she does not receive feedback on her journey from the consultant-led service. Jane's options are not discussed with her, and she is not involved in any shared decision-making process about her care. Jane decides to see her GP to discuss anxiety about her condition and its treatment.

> Switching anti-VEGF treatment may be considered if there are practical reasons for doing so – for example, if a different drug can be given in a regimen the person prefers.[5]

Jane's vision persistently worsens as she misses more injections and rescheduled appointments are delayed. About two years after her initial diagnosis, her vision has deteriorated to 6/18, and she has a fall after misjudging a step. The ambulance crew that attend are satisfied that Jane has not broken any bones, but she sees her GP, who refers her for physiotherapy for an injured ankle. Jane sees her GP repeatedly to discuss her declining vision and continuing concerns about the erratic treatment and its implications. She is clearly anxious and depressed about the situation and the GP therefore prescribes an antidepressant, contacting the hospital to share their concern about the missed appointments and the deterioration in her mental health.

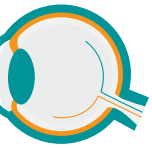
> Clinicians should be aware that people with AMD are at increased risk of depression, which should be identified and managed in line with NICE guidance on depression in adults with a chronic physical health problem.[5]

After another year, Jane's vision has declined to 6/36 but remains above the legal driving standard in her right eye. She is not referred to an eye care liaison officer (ECLO) or low vision assistant (LVA) support service, as this is not commissioned in her area.

> In the UK, to meet the legal eyesight standard for driving a car, patients must be able to read a number plate from 20 metres and visual acuity must be at least 6/12 on the Snellen scale with both eyes open or in the functioning eye if the person has sight in one eye only (wearing glasses or corrective lenses is allowed).[25]

Jane's vision rapidly deteriorates over the next few months to the point of only counting fingers. Six months later she has developed permanent structural damage, to the point where treatment will no longer be beneficial in terms of saving her sight and is stopped. Jane is discharged from the ophthalmology service without follow-up – even for the right eye that has dry AMD.

> Monitoring of late AMD (wet active) is important for identifying changes in the eye associated with the condition. Monitoring supports treatment planning, which helps to avoid under-treatment, which could result in loss of vision, and over-treatment (unnecessary anti-VEGF injections), which could be associated with harm and affect quality of life.[24]
>
> **Adults with active wet AMD should have ongoing monitoring for both eyes.**[24]



Jane's experience

Jane receives her first injection appointment in the post a week after her hospital appointment. Coming to terms with her diagnosis of wet AMD, she is relieved to be starting treatment.

Jane understands the importance of her injections but struggles to attend all of her appointments. She cannot drive herself because both eyes require examination at appointments and her friend cannot always give her a lift. Jane cannot afford taxis on her small pension, and hospital transport – if available on appointment days – can involve pick-ups 3–4 hours before and after her appointment. Some appointments are also postponed by the hospital, and delays in rescheduled appointments, which she often has to chase, means she is not receiving all injections on the monthly schedule.

Jane is stressed by the missed appointments and notices a decline in her eyesight, with reductions in central vision and reappearance of blurry and wavy lines that affect her reading and stop her taking part in usual activities, such as volunteering at the library.

Jane's vision deteriorates to the point where she has a fall at the supermarket when stepping from the pavement onto the road, injuring her ankle and requiring physiotherapy. This fall really shakes Jane's confidence, and she feels down about the situation.

Over time, life becomes much less easy and enjoyable for Jane. She is extremely concerned about her declining vision and feels depressed about her situation. The sight in her right eye with dry AMD has also declined. She has a lack of confidence about going out and running her errands, fearing mis-stepping and falling again. She avoids driving unless absolutely necessary, thinking she could pose a risk to others, so now only has access to the local convenience shop as she is fearful of falling using the bus into town.

Even going out and working on her garden feels a chore, and she often neglects the general upkeep that once gave her such joy. She can no longer read her novels and withdraws more from her usual activities, feeling increasingly isolated and shut off from those around her and society.

Jane is told that her left eye has progressed to the point of permanent structural damage, so treatment will no longer be beneficial and will be discontinued, and there is nothing further the doctors can do. She is devastated by the news but all she can do is accept it with grim resignation. She requires support from a carer, but as she retains vision in her right eye, she is not eligible to be certified as partially sighted.

A certificate of vision impairment allows easier access to services and support for adults with AMD.[24] The certificate is usually completed in secondary care and includes a formal referral for a social care needs assessment due to vision impairment and discussion of the additional benefits of registration. Completing and submitting the form as soon as a person is eligible, rather than waiting for treatment to finish, allows earlier access to services and support, which can help people retain or regain their independence and improve their wellbeing and quality of life.

All people with AMD should be offered a certification of visual impairment as soon as they become eligible, even if they are still receiving active treatment.[5,24]

Although Jane is grateful for the treatment she has received, she felt isolated throughout the journey, as she did not receive any feedback from the service and was not included in any shared decision-making. The news that she is being discharged is devastating, and with no support mechanisms in place, Jane feels more isolated than ever, facing a difficult path ahead alone.

Optimal pathway

Ongoing treatment

Having received her first injection on the day of her initial consultation at the one-stop clinic, Jane attends for her second injection of anti-VEGF treatment four weeks after her first injection. Unfortunately, she is unable to attend the appointment for her third anti-VEGF injection, but the Failsafe Officer contacts her to rearrange the appointment, offering a number of additional dates and different locations. Because extra capacity is factored into the system for such situations, Jane is offered an appointment at an alternative location early the following week. She therefore receives her third anti-VEGF injection to complete the loading phase within the recommended 10-week loading period.[8]

Jane started treatment on a more durable agent to try and minimise the frequency of appointments during her treatment. This means that after her initial three monthly loading doses, she enters the treat and extend pathway and her next injection data is booked for 8 weeks. This is arranged during the appointment and is again written down for her in a booklet.

Jane continues to receive injections as per her treat-and-extend plan. As everything is fine and her central vision is clear at the seventh appointment, the clinician extends Jane's next injection date by four weeks. At Jane's 10th injection appointment, the clinician at the consultant-led clinic is happy with her condition and discusses her care with her, engaging in timely shared decision-making, and moving her to a 16-week schedule for injections. Although Jane experiences one injection cancellation due to staff sickness, most injections are given as planned on the 16-week schedule.

During treatment, the senior nurse practitioner considered referring Jane to the local ECLO and LVA support service. However, after consulting with Jane, this was not deemed necessary.

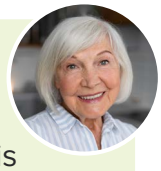
> NICE recommends considering referring people with AMD causing visual impairment to low-vision services.[5]

When Jane's condition is reviewed after her 13th injection, the consultant-led service is happy with her progress and moves her to a virtual clinic. Treatment is stopped and Jane is observed virtually every three months for the next two years. During her second virtual assessment, the clinician conducting the review informs her that their locality is participating in a clinical trial, and Jane is offered the option to be recruited into this trial for the dry AMD in her right eye, which she accepts.

> GIRFT states that virtual clinics can play an important part in providing monitoring and support cost-effectively for 'stabilised' wet AMD patients, freeing up capacity and space in the hospital while providing essential diagnostic assessment for patients.[9]

Jane continues on three-monthly virtual clinics for another year before moving to patient-initiated follow-up (PIFU) for a further year. Her vision at this point is 6/12 in her affected eye.

NICE recommends advising people with late dry AMD or with AMD who have been discharged from hospital eye services to self-monitor their AMD, consult their eye-care professional as soon as possible if their vision changes, and continue to attend routine sight-tests with their community optometrist.[5] For people being monitored for wet AMD, both eyes should be monitored at appointments.[5,24]



Jane's experience

Jane notices an improvement in her vision after the loading phase of injections. She is relieved that treatment has begun but worries about the road ahead, so she attends a coffee meeting organised by the Macular Society. She chats to others about their mutual condition and leaves feeling energised. With a new support group, she is less anxious and more optimistic about her journey ahead and plans to attend the next meeting.

Because upcoming injection appointments are pre-booked and written down for Jane, she can plan for her friend to drive her to appointments and make alternative arrangements with her son if this is not possible. If neither her friend nor son can take her, she uses the hospital transport system available to patients who otherwise cannot attend appointments under guidance from the Failsafe Officer. Although Jane has to cancel some appointments – and the clinic also cancels some – appointments are quickly rescheduled so she does not feel she is missing treatments.

Jane regularly discusses treatment with her clinician to discuss next steps. This, combined with Jane being on a more durable agent, enables a smoother transition to the treat-and-extend model, in which she needs to attend fewer appointments at longer intervals. Jane accepts the opportunity to participate in a clinical trial for her right dry AMD eye, as she can contribute to improvements in care for people with her condition. Together, Jane and the senior nurse practitioner decide that referral to the ECLO and LVA support service is not necessary. Throughout the journey, Jane feels she has a say in her own management.

As treatment continues, Jane feels better about herself and day-to-day life. She has noticed a marked improvement in her vision: lines that once seemed wavy are now straighter and her central vision is clear. The consultant is happy with her condition, so she stops treatment and is placed on a virtual clinic assessment model and later PIFU.

With regular treatment and follow-up, Jane retains her vision and still feels comfortable driving. Four years after her journey with wet AMD began, she continues living a mostly independent life, knowing that she can contact the service if the vision in her wet AMD eye should deteriorate.

Key benefits of Jane's optimal journey

Comparing Jane's final outcomes for the suboptimal and optimal pathways starkly illustrates the disparity in care, with Jane being blind in her left eye and requiring carer support after the suboptimal pathway but retaining her vision and living a mostly independent life after the optimal pathway.

Figure 2 summarises the key milestones in Jane's suboptimal and optimal pathways. Differences in the two journeys begin at the start of Jane's initial diagnosis of early dry AMD and extend through to follow-up and discharge.

- Useful information and guidance given when Jane is diagnosed with dry AMD and increased awareness from public health campaigns means that she is proactive in seeking help for the sudden change in her vision.
- Jane's optometrist understands the importance of a good quality urgent referral and what information the hospital needs to take best next steps, which allows the consultant to make an early diagnosis and arrange a prompt first appointment.
- Jane is given information about her condition before her first appointment and after her diagnosis is confirmed, both verbally and in the form of patient leaflets to review at home, which reassures her and ensures she is informed at her first hospital appointment and throughout her journey.
- Jane is signposted to the Macular Society, which means she can obtain further patient-centred information and benefit from peer support.
- Jane's first appointment is at a one-stop diagnosis and injection clinic, where her diagnosis is confirmed and she receives her first injection.
- Jane is included in a shared decision-making process, with choices made with her input, for her benefit and suiting her needs, which means she feels heard, informed and actively involved throughout her journey.
- Jane's clinicians have all treatment options available, which allows them to personalise treatment by selecting the product most appropriate to her individual circumstances. She can be started on a more durable anti-VEGF treatment, which later allows her injection intervals to be extended more through the treat-and-extend pathway, reducing the treatment burden for Jane and the hospital eye service.
- Jane is given a choice of time and location for appointments that are convenient to her, with easy access to check them herself, and sufficient advance notice to make arrangements for transport or request available hospital transport when needed, which means that she is able to attend more of her appointments on schedule.
- The clinic has sufficient capacity to ensure that recommended targets are met, with Jane starting treatment within 14 days of referral and completing her loading phase of three intravitreal injections within 10 weeks.
- When appointments cannot go ahead as planned, the system has flexibility and capacity, which means that postponed appointments can be arranged quickly at a time and location that suits Jane, and she consequently receives most of her injections on schedule. A Failsafe Officer is also available to follow up missed appointments and reschedule appointments.

- Jane has access to an ECLO and LVA support service, which are commissioned in her area.
- Jane's dry AMD is monitored alongside her wet AMD, and she is offered the opportunity to enter a clinical trial.
- Jane maintains her vision over her journey and is eventually able to stop treatment when her vision is stable and her macula remains dry.
- After Jane's treatment is stopped, she is followed through virtual consultations and switched to PIFU, so she has immediate access to the hospital eye services if her vision deteriorates.

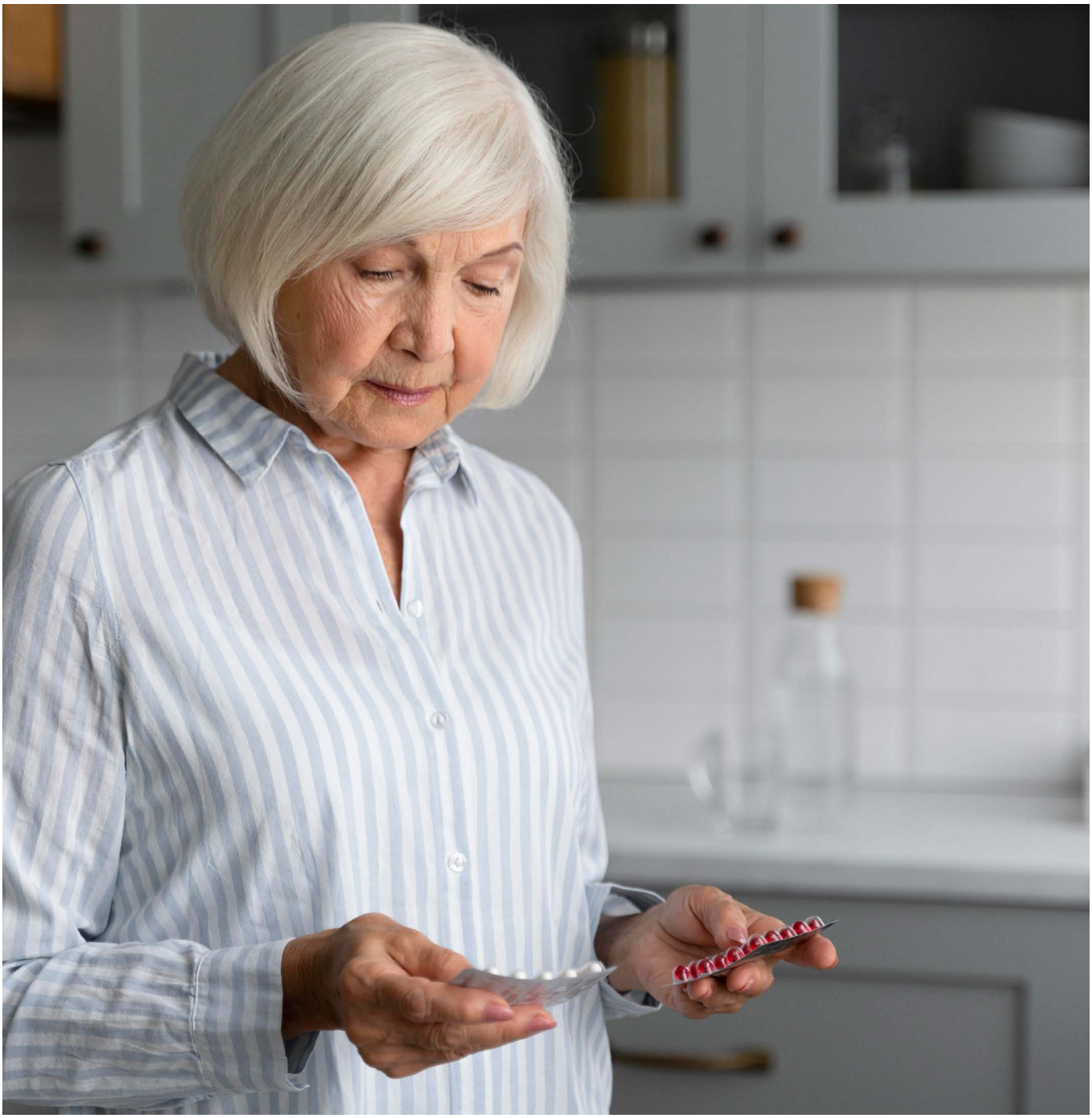
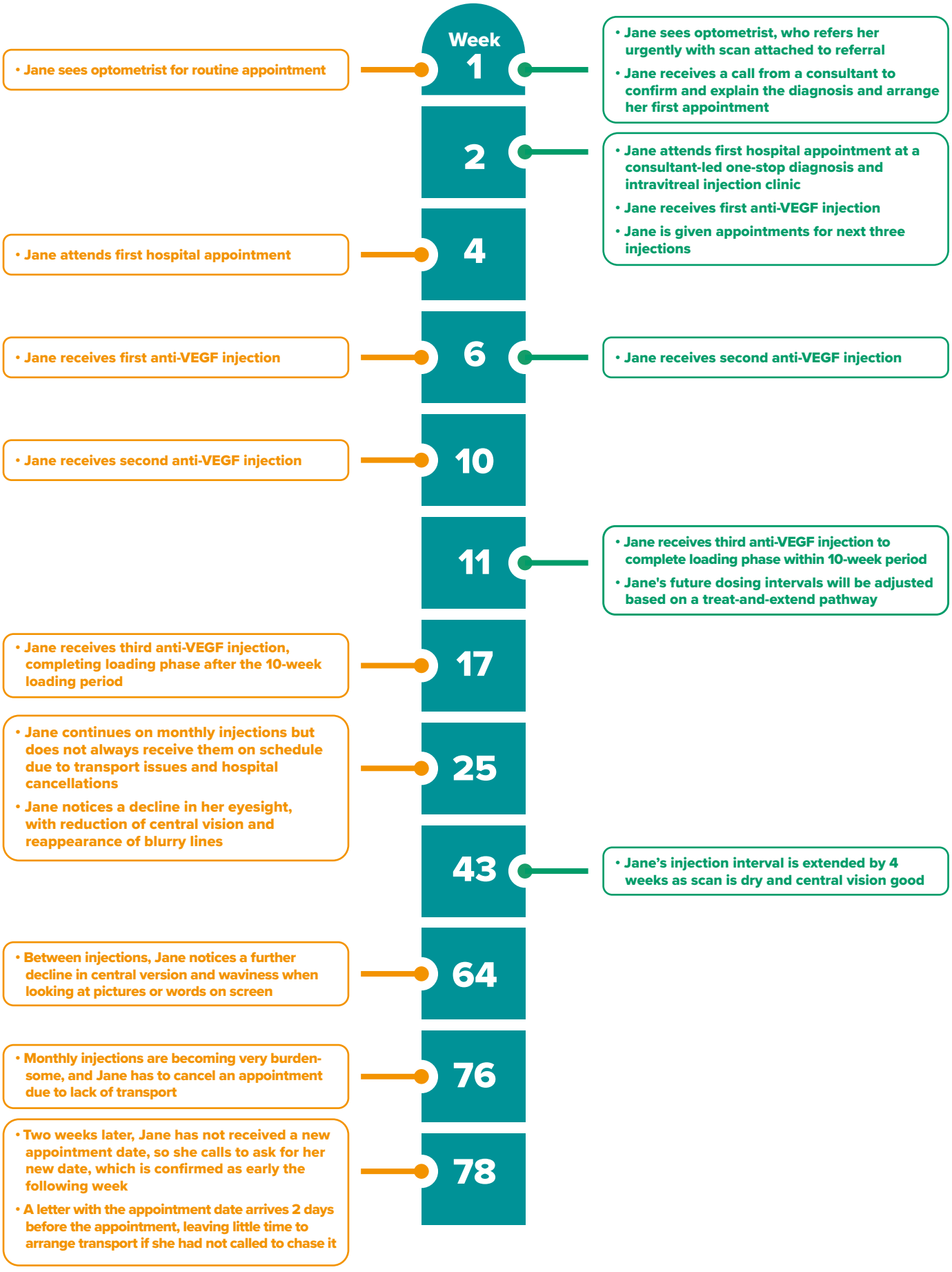


Figure 2: Key milestones in Jane's suboptimal and optimal pathways.



Week 79
- Jane moves to 16-week schedule for injections as her consultant is happy with her condition

95
- Jane receives a call cancelling her next appointment but the Failsafe Officer calls to rebook a rescheduled appointment that takes place later the same week

111
- Jane has call from the hospital cancelling her next injection
- Jane has a fall after misjudging a step off the pavement onto the road due to declining vision and requires physiotherapy on an injured ankle

115
- Jane continues to notice declines in her vision

127
- Jane's vision remains stable
- Although ECLO and LVA support are available, Jane does not need them

131
- Jane's vision declines further, and she panics about losing her sight

143
- Jane stops treatment and is to be observed virtually every 3 months for the next 2 years as the consultant is happy with her progress

168
- Jane's vision in her left eye deteriorated below the driving standard but her right eye retains enough vision to legally drive, although she prefers not to
- She is not offered ECLO or LVA support service, as this is not commissioned in her area
- Jane is offered the option to be recruited into a clinical trial for the dry AMD in her other eye, which she accepts

180
- Jane's vision has quickly deteriorated further over the last few months

183
- Jane is informed that her eye has progressed to the point of permanent structural damage, treatment will no longer be beneficial, and her treatment pathway is ending.
- No follow up is arranged, even for her dry AMD eye

208
- Jane continues on 3-monthly virtual clinics for another year before moving to PFIU for a further year

Jane is blind in her left eye and requires support from a carer

Four years after her initial diagnosis of wet AMD, Jane retains her vision and continues living a mostly independent life

The costs: how the two pathways compare

A financial evaluation was performed by mapping the activities involved in the suboptimal *versus* optimal management pathways for Jane, a fictional 80-year-old patient diagnosed with wet AMD. This analysis highlights the projected cost differences and resource utilisation associated with each pathway (Table 1), providing indicative insights for service transformation teams considering the implications of different treatment approaches from both quality-of-life and cost perspectives.

Through this process, it is possible to identify the cost drivers incurred across community, primary and hospital care settings. The costs presented are based on assumed unit costs for specific activities, consultations, diagnostics, procedures and medications derived from sources analogous to the NHS National Tariff Payment System and Unit Costs of Health and Social Care.[26,27] The key cost areas included are:

- unit costs of community, primary and secondary health care services
- staff costs associated with consultations, procedures and administration
- drug costs (primarily anti-VEGF treatment)
- costs associated with transport (ambulance and patient transport services).

Although the qualitative impacts are considered, this analysis does not include the costs outside the direct health remit or the wider social, emotional, physical and financial costs to our fictional patient Jane and her family members.

The financial costs presented are indicative and calculated on a cost-per-patient basis for this specific fictional case. This case outlines both the optimal and a suboptimal — bordering on worst-case — scenario journeys. However, in practice, systems can be operating between the

Table 1. Summary of costs in the optimal and suboptimal pathways.[26,27,35]

Cost category	Cost subcategory	Suboptimal pathway (£)	Optimal pathway (£)	Cost difference for optimal pathway vs suboptimal pathway (£)
Community care	Other	96	24	–72
	Subtotal	**96**	**24**	**–72**
Primary care	Consultations	315	90	–225
	Drugs*	84	–	–84
	Subtotal	**399**	**90**	**–309**
Secondary care	Ambulance	327	–	–327
	Drugs†	22,101	11,574	–10,527
	Injection procedures	5,494	2,184	–3,310
	Transport	–	28	+28
	Other	401	949	+548
	Subtotal	**28,323**	**14,735**	**–13,588**
Total		28,818	14,849	–13,969

Costs have been considered using NHS tariffs and adjusted based on assumptions on NHS practices as per NHS RightCare.
*Antidepressants: average cost of three commonly used drugs.[28–30]
†Optimal pathway: durable anti-VEGF agents;[31–33] suboptimal pathway: non-durable anti-VEGF agents.[32,34]

described optimal and suboptimal pathways. Local decisions to transform care pathways would need to take a population view of costs and improvement, considering local commissioning arrangements, contract types and actual incurred costs, which may vary.

The most marked outcome is the impact of the suboptimal care pathway on Jane's quality of life, independence and overall health (Table 2). Delays in diagnosis and treatment initiation, multiple appointment cancellations and rearrangements, and a lack of proactive support contributed significantly to disease progression and complications. In the optimal pathway, streamlined processes and proactive support lead to differences between the two pathways.

Table 2. Key differences between the suboptimal and optimal pathways.

Suboptimal pathway	Optimal pathway
• Standard treatment regimen with fixed treatment protocol • Treatment delays • Significant appointment burden • Cancellations leading to anxiety, disease progression requiring low vision aids, physiotherapy (potentially due to falls or adjustment issues), domiciliary assessment, and treatment for depression	• Rapid diagnosis and timely treatment initiation via a one-stop diagnosis and intravitreal injection clinic model • Durable agent which allows for more flexibility in treatment protocols which can flex to patient and system needs • Receiving psychosocial support via referral to the Macular Society • Benefiting from efficient follow-up, including virtual reviews • Maintaining functional vision for longer
Jane loses vision in one eye, resulting in loss of confidence and independence	**Jane's sight is stabilised, resulting in little change in independence and quality of life**

The broader system impact of managing Jane via the suboptimal pathway is considerable, with an indicative system cost difference (potential saving) of £13,969 (£28,818 suboptimal vs £14,849 optimal) throughout the mapped care pathways of 208 weeks. This suboptimal patient journey is associated with significantly higher resource utilisation (Table 3 in Appendix) than the optimal pathway (Table 4 in Appendix). Key differences include:

- increased secondary care activity – more injection appointments, follow-up visits and administrative tasks (phone calls for rearrangements)
- management of complications – physiotherapy and associated GP consultations/prescriptions (e.g. antidepressants)
- higher emergency/unplanned costs – use of ambulance service
- substantially higher drug costs (£22,101 *versus* £11,574) – due to monthly injections for a extended time period compared with the optimal pathway with a durable agent, which achieves stability sooner
- higher primary care utilisation – more GP consultations.

While specific workforce hours per team (e.g. nursing, ophthalmology, administration) were not explicitly calculated in this model, the substantially higher number of appointments, interventions and administrative contacts (e.g. phone calls for rescheduling) in the suboptimal pathway strongly indicate a substantially greater workforce burden compared to the optimal pathway.

This costing was for the duration of the mapped pathways and does not take account of:

- ongoing costs associated with potentially irreversible vision loss in the suboptimal pathway
- potential need for formal social care support if independence is lost
- ongoing impact on Jane's mental health and wellbeing
- potential burden on family carers should Jane's needs increase substantially.

Financial calculation notes

- As noted above, the financial calculation presented here represents an indicative level of efficiency potential of the case only.
  - As the case is a fictional example pathway, different pathways may increase or reduce the potential benefit for other patients.
  - The possible release of resources associated with implementing the optimal pathway across a larger cohort of patients will be subject to overarching contractual arrangements, which may differ across the country. For example, some of the financial benefits identified in this fictional case may not be fully realisable where the pathway elements are subject to block contracts or risk/gain shares in place between contracting parties. Equally, the release of resources may only be realised should there be a critical mass from within the targeted patient population.
- The financial calculation is considered from a service transformation perspective. The impact on provider organisations' income and costs (including capacity management) will require consideration in implementing the optimal pathway.
- Each healthcare organisation and system must assess the potential for realising the financial benefits identified in the case.
- While a journey of fixed dosing anti-VEGF injections has been selected for the suboptimal pathway in this report, some less durable agents can utilise treat and extend protocols, which could see a reduction in costs related to drugs over the specified time period.
- Drug costs have been averaged (durable and non-durable anti-VEGF drugs and antidepressants) using British National Formulary (BNF) costings and do not account for any potential confidential price agreements via patient access schemes (PAS) with the NHS.
  - Three durable anti-VEGF agents were selected for the optimal pathway and averaged to give a unit cost of £890 per dose.[31-33] Two non-durable anti-VEGF agents were selected for the suboptimal pathway and averaged to give a unit cost of £670 per dose.[32,34] These costs were then multiplied by the number of injections in each respective story to give total anti-VEGF drug costs.
  - Three antidepressants were selected and averaged to give a unit cost of £1.40 per dose.[28–30]
- Assumption that one injection vial containing the anti-VEGF agent is used per injection (i.e. vials are not shared between patients within a treatment session).
- Where a cost was not available in the literature, estimates have been made under guidance from an NHS advisor.[36]

Learning points

Key improvements can be made at all stages in the patient pathway for wet AMD – from community optometrist referral through management in hospital eye services and beyond discharge.

Education

- Optometrist awareness of criteria for referral, information to include in referrals and which conditions require urgent/emergency referral
- Awareness of the guidance on management of AMD in the UK
- Understanding of which diagnostic techniques should be used
- Understanding the impact of the choice of anti-VEGF agent in terms of the patient experience
- Signposting patients to patient organisations and resources such as the Macular Society for information and peer support

Communication

- Providing patients with a copy of their referral letter
- Providing optometrists with feedback on quality of referrals and confirmed diagnosis to improve future referrals
- Providing patients with clear information about their suspected condition, including signs and symptoms that it may be progressing and what to do if their vision deteriorates, as well as information about what to expect in hospital appointments, treatment choices, different injection models, and NHS support available to them
- Discussing the management pathway and location of care with patients assessing, their individual needs and involving them in the decision-making process throughout their journey
- Introducing coordinators who are linked with patients through their journey

Digital

- Updating systems to improve information access and improve coordination between community optometry and hospital eye services
- Updating and improving booking and administrative systems
- Developing digital tools and formats that could support patients, such as videos and versions of support information in different languages

Conclusion

This Cost Integrated Patient Scenario (CIPS) analysis demonstrates the marked potential differences in care that a patient with wet AMD can receive and the impact this can have on patient outcomes and system costs.

The impact on the patient herself is perhaps the most notable difference. In the suboptimal pathway, Jane loses sight in one eye and requires support from a carer, with a greatly reduced quality of life and unnecessary distress. In the optimal pathway, Jane retains her vision and maintains a mostly independent life, while at the same time potentially generating significant economic savings of £13,969 for the NHS and the taxpayer in the process.

Good communication between healthcare professionals and the patient in the optimal pathway results in a more positive care experience for the patient – Jane feels heard and involved in her own care process and consequently has better understanding of her condition from the initial diagnosis of early dry AMD and throughout development of wet AMD and its initial diagnosis and ongoing management. All available treatment options are accessible to Jane, including durable agents, and in collaboration with her clinician, she is able to select the most appropriate one — reducing the burden of regular injections and promoting a more positive patient experience. An efficient and resilient service also ensures that she receives her injections on schedule, as often as possible, ultimately improving her final outcome.

The key difference between the suboptimal and optimal pathways in terms of cost is determined by the type of anti-VEGF agent used, with durable rather than non-durable treatment leading to fewer injections, lower consultation and procedure costs, and early transition to a treat-and-extend model. Additional cost differences include community care costs as she attends her GP more often due to anxiety and depression over her failing sight, for which she is prescribed an antidepressant, and following her sight-related fall, which also incurred costs related to ambulance attendance and physiotherapy.

Useful resources

College of Optometrists

- Guidance for professional practice: https://www.college-optometrists.org/clinical-guidance/guidance/communication,-partnership-and-teamwork/working-with-colleagues/referrals
- Urgency of referrals: https://www.college-optometrists.org/clinical-guidance/guidance/guidance-annexes/annex-4-urgency-of-referrals-table

GIRFT

- Ophthalmology national specialty report: https://gettingitrightfirsttime.co.uk/wp-content/uploads/2019/12/OphthalmologyReportGIRFT19S.pdf

NICE

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National Ophthalmology Audit

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- 2025 AMD audit – patient summary https://nodaudit.org.uk/sites/default/files/2025-03/NOD%20Audit%20AMD%20Patient%20Summary%202025_Final.pdf

Royal College of Ophthalmologists

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Abbreviations

AMD	age-related macular degeneration
BNF	British National Formulary
CIPS	Costed Integrated Patient Scenario
CNV	choroidal neovascularisation
ECLO	eye care liaison officer
eERS	electronic eye referral service
FFA	fundus fluorescein angiography
GIRFT	Getting It Right First Time
GOS	General Ophthalmic Service
GP	general practitioner
ICGA	indocyanine green angiography
LVA	low vision assistant
NICE	National Institute for Health and Care Excellence
NOD	National Ophthalmology Database
OCT	optical coherence tomography
OCT-A	optical coherence tomography angiography
PAS	patient access scheme
PED	pigment epithelial detachment
PIFU	patient-initiated follow-up
RCO	Royal College of Ophthalmologists
RPE	retinal pigment epithelium
VEGF	vascular epithelial growth factor

Appendix

Table 3. Suboptimal scenario costing breakdown.[26,27,35]

Resource/activity		Quantity (n)	Total costs (£)
Community care	Routine optometrist sight test (GOS)	1	24
	Physiotherapy assessment	1	41
	Physiotherapy follow-up	1	31
	Subtotal	**3**	**96**
Primary care	GP consultation	7	315
	Antidepressant*	60	84
	Subtotal	**67**	**399**
Secondary care	Ambulance call-out	1	327
	Anti-VEGF drug†	33	22,101
	Consultant-led outpatient attendance	1	161
	Consultant-led follow-up outpatient attendance	1	73
	Injection visits (includes visual acuity checks and OCTs)	33	5,494
	OCT scan (hospital diagnostic)	1	167
	Subtotal	**70**	**28,323**
Total		140	28,818

Costs have been considered using NHS tariffs and adjusted based on assumptions on NHS practices as per NHS RightCare. Drug costs do not account for any potential confidential price agreements via patient access schemes (PAS) with the NHS.
*Antidepressants (average cost of three commonly used drugs).[29–31]
†Non-durable anti-VEGF agents.[32,34]
GOS, General Ophthalmic Services; GP, general practitioner; OCT, optical coherence tomography; VEGF, vascular endothelial growth factor.

Table 4. Optimal scenario costing breakdown.[26,27,35]

Resource/activity		Quantity (n)	Total costs (£)
Community care	Routine optometrist sight test (GOS)	1	24
	Subtotal	**1**	**24**
Primary care	GP consultation	2	90
	Subtotal	**2**	**90**
Secondary care	Anti-VEGF drug*	13	11,574
	Consultant-led phone consultation (diagnosis)	1	17
	Consultant-led first appointment (One Stop Clinic)	1	177
	OCT scan	1	167
	OCT-A	1	167
	Consultant-led follow-up appointment	1	86
	Failsafe Officer phone call	2	10
	Injection visits (includes visual acuity checks and OCTs)	13	2,184
	NHS Patient Transport Service	1	28
	Virtual clinic assessment	5	325
	Subtotal	**39**	**14,735**
Total		42	14,849

Costs have been considered using NHS tariffs and adjusted based on assumptions on NHS practices as per NHS RightCare. Drug costs do not account for any potential confidential price agreements via patient access schemes (PAS) with the NHS.
*Optimal pathway: durable anti-VEGF agents.[31–33]
GOS, general ophthalmic services; GP, general practitioner; OCT, optical coherence tomography; OCT-A, optical coherence tomography; VEGF, vascular endothelial growth factor.

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