



Working for People
with Sight Loss

Patient experience research study:



Experience of patients living
with wet Age-Related Macular
Degeneration (wet AMD)

Supported by Bayer



Foreword

Age Related Macular Degeneration (AMD) is the most common cause of vision impairment in Ireland among people over the age of 50 [1], resulting in the degeneration of the person's central vision.

Whilst medical treatment options are available for wet AMD, timely access to rehabilitation and community-based supports remain a key determinant of successful treatment plans. Given the magnitude of the impact of wet AMD on a patient's livelihood and lifestyle, meeting the physical and mental health needs of the patient population is an increasing challenge - a challenge that will only grow over time in the absence of a collective response.

One of the core principles underpinning Sláintecare is to provide universal access to healthcare based on need, advocating for an increased focus on the delivery of services in the community, where appropriate. Sláintecare aligns with the recommendations of the Primary Care Eye Services Review Report (2017) for conditions such as wet AMD.

The need to adopt a more strategic and patient centric approach to the diagnosis, treatment and awareness of wet AMD is critical. Based on the findings of this research project, NCBI are calling on the State to implement the recommendations of Sláintecare and the Primary Care Eye Services Review Report. The development and implementation of clear timelines around the diagnosis, treatment and management of the condition, along with patient's desire to be referred to NCBI's rehabilitation services offers a real opportunity for maintaining the care, independence and the mental health needs of patients.

Support to patients experiencing wet AMD must be guided by international best practice where equity of access to treatment, rehabilitation and support is prioritised.

This research will guide NCBI's continuous commitment to highlight and seek improvement in the outcomes and quality of care for patients affected by vision impairment and blindness.

Recommendations

In response to the research findings and in an aim to reduce the impact of wet AMD on patients' health outcomes, the following recommendations have been made under four critical themes:

Importance of timely rehabilitation:

NCBI is calling on the State to:

- Meaningfully invest in vision rehabilitation services for patients living with wet AMD;
- Improve the integration of rehabilitation services into the acute setting by including NCBI's community-based teams in the roll out of the HSE's proposed Primary Eye Care Teams (PECTs);
- Support increased access to community-based services by funding and embedding NCBI's Eye Clinic Liaison Officers across all major hospital ophthalmology clinics by the end of 2021.



Patient independence and social isolation:

NCBI is calling on the State to:

- Support access to counselling services by funding 1.0 WTE qualified counsellor post per Community Healthcare Organisation (CHO) area to enhance timely access to the full spectrum of psychological supports.

Supporting patients' mental health:

NCBI is calling on the State to:

- Implement recommendations made in the Primary Care Eye Services Report (2017) to move the point of care for appropriate conditions, such as wet AMD, out of acute hospitals into primary care in the community;
- Increase awareness and access to services by embedding community-based resources within the Primary Eye Care Teams.

Supporting public awareness of AMD and clinical medical experience

NCBI is calling on the State to:

- Improve awareness of AMD and the importance of regular eye checks, particularly for people over the age of 50 within the Irish population;
- Develop guidelines to stipulate a timeframe for diagnosis and treatment. Guidelines should be in line with the UK derived NICE Guidelines for late AMD which recommend:
 1. 1-day referral to a hospital-based macular service from general ophthalmology or other healthcare professionals such as GPs and optometrists;
 2. 14 days for treatment from referral date if 'wet active' AMD is confirmed.

About NCBI

NCBI, Ireland's national sight loss agency, is a not-for-profit charitable organisation which provides community-based support services for people with vision impairment and their families. NCBI offers a range of services aiming to support independence, including emotional support and counselling; advice and information; and rehabilitation training to people of all ages nationally.

Approximately 1 in 3 new referrals to NCBI have a primary diagnosis of AMD.

About Age Related Macular Degeneration (AMD)

AMD is the most common cause of sight loss in Ireland among people over the age of 50 [2]. AMD affects the macula of the retina, a small area located at the back of the eye, resulting in a loss of central vision, which is important for driving, reading and facial recognition. Whilst AMD can result in degeneration of sight and impact on quality of life it rarely leads to complete loss of vision.

Approximately 7% of people over the age of 50 will develop AMD in Ireland [3].

There are two main types of AMD - dry AMD and wet AMD. Like many eye conditions, the early stages of dry AMD are asymptomatic and can only be detected through an eye test. There are currently no medical treatments available for dry AMD, however, research efforts to develop therapies to prevent or treat this condition are on-going.

Around 10-15% of people with dry AMD progress to develop wet AMD [4]. Whilst less common than dry AMD, wet AMD can develop faster resulting in a rapid loss of vision. In most cases, if diagnosed and treated early, deterioration in vision can be slowed, maintained, or recovered.

Research regarding patient quality of life is of particular interest to the NCBI to inform policy and patient advocacy priorities. As the Irish population increases and ages, the incidence of people with

age-related vision loss will increase, and this will consequently increase demand on services. It is expected that by 2030, the population of people over the age of 65 will increase to 1 in 6 people, close to 1 million people [5], resulting in an increased need for services for conditions that are inherently age related, like AMD.

About the research

As part of its advocacy remit, NCBI commissioned Forum Research, an independent research company with expertise in patient research, to gather insights into the experiences of patients living with wet AMD. The research aimed to investigate the patient experience from onset of initial symptoms, through diagnosis and treatment, and the impact of the condition on their lives. Research was conducted in 2019, prior to the Covid-19 pandemic.

The research findings and subsequent recommendations presented in this report are of relevance to policy makers and service providers including the Government, Department of Health, Oireachtas Committee on Health, the HSE, acute hospital management, clinicians, disability and service providers for older people, and the NCBI itself.

This research project was supported by Bayer, the life sciences company.

Methodology

Forum Research employed a mixed methods approach to the research involving qualitative and quantitative research.

- Phase 1: Qualitative: 7 in-depth face to face / phone interviews were conducted amongst people living with wet AMD to understand its impact on their lives and their experiences of engaging with the health care system. Information from this phase informed the development of the questionnaire used in Phase 2.

- Phase 2: Quantitative: 124 people participated in either a phone or online survey. All were active NCBI service users with a confirmed diagnosis of wet AMD. 100 people participated by phone and a further 24 people participated online. The latter included NCBI services users contacted by NCBI by email and the wider public contacted through NCBI social media pages. Feedback from all 124 responses were cross tabulated with cross breaks chosen based on groups of interest.

The findings shared are drawn from the quantitative research (Phase 2) with verbatims from the qualitative research (Phase 1).

Profile of participants

Using NCBI's customer management system, clients with a formal diagnosis of wet AMD were randomly selected for interview. In total, 131 people participated (Phase 1: 7 participants, Phase 2: 124 participants). The demographic profile of participants of Phase 2 showed they were in an older age group (57% were over 80 years of age, 27% age 71-80 and 15% under 70 years of age), 62% had been diagnosed within the last 4 years and 38% more than 5 years ago.

There was almost an equal gender balance amongst participants (48% female, 52% male) and among those attending the public and private healthcare system (50% private patients, 49% public patients, 1% not stated). 40% of participants attended hospitals in Dublin, 54% outside Dublin and 6% not stated.

Patient experience research

Analysis of the research findings can be summarised under four key themes.

Maria McAuley's story

Eighteen months ago, Maria woke up and noticed that she could not see that well. She got an appointment with her local optician that day who referred her to her local GP. When she met her GP, she told Maria to go straight into the Emergency Department of the Eye and Ear hospital in Dublin. It was here that she was diagnosed with Age Related Macular Degeneration (AMD). Within 4 days, the fluid behind Maria's eyes had been removed and she got her first injection into both of her eyes. Maria now gets an injection once a month.

Maria's mother had AMD so she was familiar with the condition and how it can affect a person's daily life, but she would have liked more information about the condition particularly when she received her initial diagnosis. When the hospital told her that she was "clinically blind" she found it very distressing. She felt that she could not see very well yet, she was not totally blind and did not know where to turn. She could no longer see to read books or signs and had to give up driving which was huge change in her life.

Early on in her diagnosis, a nurse at the Eye and Ear hospital suggested that she contact NCBI. Maria said that she found the supports that NCBI offers to be of great benefit to her. She feels that NCBI are at the end of the phone if she needs advice on something. NCBI has provided her with a symbol cane, so that others would be aware that she has a problem with her sight and might need assistance. She also finds the handheld magnifier that she got from NCBI to be helpful to read small print and she also avails of NCBI's audio book service.

Since the onset of her eye condition, even though she is not of retirement age, Maria decided to give up working for a charity as a Development Worker. She said that she would struggle to use a computer for work and would also find it very difficult to use public transport. Maria's family and friends have been a great support to her. They invite her to go places and get out and about.

With the support of NCBI, Maria feels that she has adjusted to living with her vision impairment and is happy that she can manage to do the things that she wants to do.

Theme 1 -

Importance of timely access to rehabilitation

Research findings

- Almost 4 in 10 participants (37%) had reduced their daily activities because of their wet AMD, whilst almost 1 in 3 had reduced / stopped driving (30%).
- More than half of the participants wanted help and advice to be able to walk with confidence (55%) and watch TV (59%) while almost two-thirds wanted help and advice with reading newspapers, books or magazines (63%).
- 80% of participants were receptive to receiving vision rehabilitation supports from NCBI in their community.
- 89% of participants wished to receive information on supports and services available in the community.

“I would be interested in attending an information day or seminar about macular degeneration, the causes, the future, unanswered questions. We are literally in the dark about it. I’d be happy to meet other people with macular degeneration.”

Female, 80s, private patient, living in Dublin.

“People at the clinic told me to go to NCBI; I got a cane, magnifiers, glasses. I wanted a big reader or at least A4 size so I can read a book. I visited them three times and they called me a few times offering courses but the courses are about technology and I am no good with it and it is not based in Ballinasloe. How would I get to Limerick or Galway? It’s too far.”

Female, 70s, public patient, living in Galway.

Comment

The research results highlight the impact of wet AMD on patients and the extent to which it impacts their day to day living, particularly their independence.

Research has shown that early intervention vision rehabilitation can positively impact patient quality of life and independence [6]. Whilst almost all patients were receptive to receiving rehabilitative support in the community, the historic underfunding of Ireland's vision rehabilitation services is preventing patients from timely access to care and support across community and primary care settings.

As a result of the underutilised services, the awareness of the benefits of vision rehabilitation across eye health professionals and policymakers is consequently further diminished, exacerbating gaps in supports to improve health outcomes for patients with wet AMD. From the 3,828 referrals to the NCBI in 2019, just 12% came from ophthalmologists.

Recommendation

To reduce the impact of wet AMD on patients and their families and to meet requirements expressed above by respondents, it is imperative that timely access to NCBI's vision rehabilitation services is made available to all in order to learn techniques to utilise remaining vision.

NCBI is calling on the Government to meaningfully invest in vision rehabilitation services for patients living with wet AMD and to improve the integration of rehabilitation services into the acute setting by including NCBI's community-based teams in the roll out of the HSE's proposed Primary Eye Care Teams (PECTs) [7].

Theme 2 -

Impact of wet AMD on patient independence and social isolation

Research findings

- 60% of participants reported that their involvement with friends and family had decreased since being diagnosed with wet AMD.
- 69% of participants stated their involvement with their wider community had decreased since being diagnosed with wet AMD.

“It’s not possible to rely on your family all the time. They are busy and have young children. I am dependent on friends and neighbours to read my correspondence and letters.”

Female, 80s, private patient, living in Dublin.

“You are given a phone number for the eye specialist on call if you have problems after treatment, that’s it. You need a bit of TLC along the way; somebody who knows the process and knows how to be empathetic.”

Female, 70s, public patient, living in Galway.

Comment

With extensive reporting of social isolation and reduced involvement with friends and family, it is imperative that supports are put in place to mitigate these effects and reduce feelings of isolation among patients living with wet AMD.

Research consistently shows the provision of early intervention and support at or immediately after diagnosis means patients are more likely to maintain their independence and less intensive supports are required later on to maintain or improve quality of life.

The impact of wet AMD on patient’s isolation levels can be mitigated through greater levels of collaboration across community providers



and increased utilisation of telehealth supports. From the research, patients who reported they were actively involved with NCBI were more likely to have made adjustments than those less actively involved with NCBI.

Based in major hospital ophthalmology departments, NCBI's Eye Clinic Liaison Officers' (ECLO) service is focused on responding to patient needs from the point of diagnosis. The ECLO service bridges the gap between the acute environment and community-based services and groups, by providing referrals to positive ageing supports for both patients and their families, including vision rehabilitation, counselling and emotional support, and employment retention services.

As a result of the ECLO service, 9 in 10 patients who engaged with the service in 2019 are now being actively supported to remain independent in the community [8].

Recommendation

NCBI is calling on the Government to fund embedding of the ECLO service across all major Irish hospital ophthalmology clinics by the end of 2021. This means that every patient attending a hospital eye clinic in Ireland would have access to an ECLO to safeguard their independence by connecting patients to existing supports available in the community.

Frank Peyton's story



Around 10 years ago, Frank suddenly experienced a pain in his left eye and at a routine eye check with his local optician he was told that the vision in that eye had deteriorated significantly. As a private patient, Frank was referred to see an eye consultant who told him that he had Age Related Macular Degeneration. Four years on, at his yearly check-up, the eye consultant noticed a reduction in his sight in his other eye. It was at that point, Frank decided to get the second opinion. He was able to get an appointment with an eye consultant the very next day. At this appointment, it was confirmed that he had Age-related Macular Degeneration (AMD) in both eyes but that it was best to wait a few months before treatment with injections. A few months later, Frank received injections in his eyes and has continued to do so for the last 10 years. He now gets injections every 6 weeks and sees his eye consultant every 6 months. Thankfully, Frank's health insurance covered the cost of the injections, but Frank must pay for each consultation with his eye consultant in his private rooms. Frank and his family did their own research online to find out more about AMD. Initially, they were terrified that Frank would lose all his sight, so he felt it was good to be informed to relieve any fears. One of the biggest losses for Frank since the onset of his AMD, is not being able to drive anymore. Frank was a taxi driver and had to immediately give up his job once he received the diagnosis. He also struggles to read the newspaper, to see signs and recognise people's faces which can be distressing and frustrating. Frank's local family doctor suggested that he contact NCBI. It is through NCBI that Frank met other men who also live with vision impairment which he felt was a great support to him. He also got a CCTV through NCBI which enables him to enlarge print onto a screen to a size he can read. Frank is now 69 years old. He loves gardening and keeps himself busy every day. He feels that his family have been a great support to him. His son and daughter help him to send email and his wife drives him to where he needs to go. Frank, however, tries to keep his independence as much as possible and uses the bus and goes shopping independently. At the shops, he uses a pocket magnifier that he got from NCBI to read the prices and labels on products. He says that he is satisfied with how he can manage daily since his sight reduced.

Theme 3 - Impact of wet AMD on patients' mental health

Research findings

- Approximately 7 in 10 participants reported that they experienced stress to some extent about their eyesight (73%) and were worried they might lose their remaining vision (69%). The frequency of experiencing either of these factors was greater amongst public patients than private patients.



- Almost half of the participants (49%) experience symptoms of depression to some extent due to wet AMD.
- Just 4 in 10 participants (41%) were satisfied with how they coped on a day to day basis living with wet AMD.

“I was shattered at diagnosis; my eyes are so important to me. I live on my own. Who will look after me if I go blind? I was traumatised and anxious. What happens when I can't travel to Galway for treatment? What happens then?”

Female, 70s, public patient, living in Galway.

“Some days I get very down but I go out with the dog and she cheers me up. You have to pull yourself up. My husband is ill also. The time you need NCBI most is early when diagnosed, when you are most upset, just to know they are there. At that stage everything seems to take forever. Six months into it I've come to terms with it more. At the moment I am just hoping the wet will clear up and I can get driving again - that loss of independence has been extremely hard. I don't want to ask people for help.”

Female, 60s, public patient, living in Dublin.

Comment

Research has shown that instances of wet AMD is correlated with reduced mental health and depression, and negative impact on quality of life [9,10,11,12]. Given the magnitude of this burden, meeting the healthcare needs of wet AMD patients is a growing challenge.

With appropriate access to high-quality counselling and emotional support, the adverse impact of wet AMD on patients' mental health can be offset through timely counselling intervention and supports. There is a pressing need to provide timely counselling supports to patients experiencing wet AMD, particularly where sight loss is sudden or rapid.

Recommendation

The States needs to fund 1.0 WTE qualified counsellor post per Community Healthcare Organisation (CHO) area to enhance timely access to the full spectrum of psychological supports.

Theme 4 -

Patients clinical experience and awareness around AMD

Research findings

- Presenting with symptoms to a GP:
Of the 62% of respondents who could recall the length of time in which they held off from seeking medical attention, 1 in 2 (51%) patients waited over 6 months before attending a doctor about their wet AMD symptoms from the time of initial onset, and 1 in 8 (12%) waited over one year.
- Presenting to a consultant ophthalmologist for diagnosis:
Of the 73% of respondents who could recall the length of time they waited before attending a consultant ophthalmologist for a diagnosis, from those who could recall, more than 1 in 4 (27%) waited over six months for a diagnosis.
- The waiting time to attend a consultant ophthalmologist was significantly different between public and private patients. Of those who could recall, 90% of private patients were seen within 6 months whereas just half (52%) of public patients were seen within 6 months.
- Commencing treatment: Of the 76% of participants who could recall when they commenced treatment, almost 4 in 10 (38%) participants stated they began treatment within 3 months of diagnosis. However, over half of participants (54%) waited over three months, 28% over six months and 8% over one year to begin treatment following diagnosis from an ophthalmologist.
- Treatment commenced sooner for private patients than public patients. On average, private patients began treatment within 3-6 months compared to 6-12 months for public patients.

- Healthcare professional continuity varied significantly between private and public patients, where 5% of public patients reported that were seen by the same medical professional versus 84% of private patients.
- On average, participants travelled 38 miles to attend a clinic for treatment. This was higher for public patients than private patients (52 vs. 28 miles). In terms of travelling to the clinic, family members or friends drove the majority of patients (85%).

“Going to the A&E is very confusing. It’s very busy with, long, long waits. It is nobody’s fault; you just must wait. Things get assessed and you move to the next part and you are waiting for the doctor to check things. The service they give is no fault of their own, it’s just the way it is. I am lucky as I live nearby. I see patients come from Donegal. I can’t complain.”

Male, 70s, public patient, living in Dublin.

“The clinic is scary, crowded and you don’t know what to expect. It is very slow, I arrived at 11am and got out at 7.30pm. After scans and results you are waiting for the doctor all of the time My stomach turned when they said injections, I was absolutely terrified. I also got a fright when they mentioned an operation. I mean prior to this I thought I only needed new glasses.”

Female, 60s, public patient, living in Dublin.

“I have seen the queues and how crowded it is in the public clinic. My God, I nearly died. I am fortunate to have insurance and I can go privately. It is very hard for older people to wait so long. For me I am in and out quick enough, a couple of hours at most.”

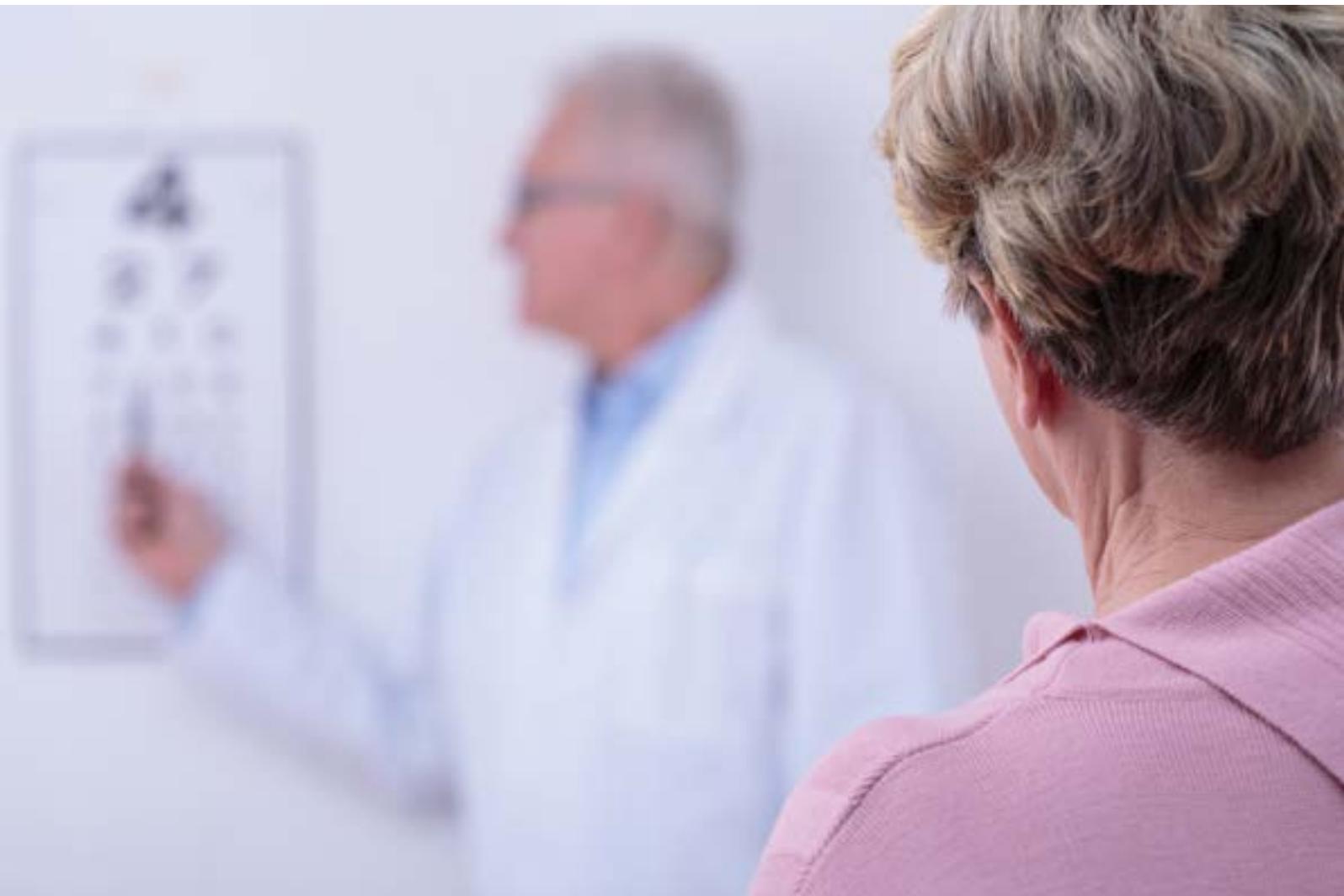
Male, 60s, private patient, living in Cork.

Comment

Prevention of serious eye disease requires appropriately resourced early detection and treatment approaches. Delays in either diagnosis or treatment can result in irreversible sight loss. Worryingly, patients in the public system, reported significant wait times from referral to attending a consultant ophthalmologist for a diagnosis and also for their subsequent first treatment.

Increased understanding amongst the public on the importance of frequent eye tests to detect disease, the signs and symptoms of AMD, in combination with access to effective treatment of wet AMD are critical to prevent avoidable sight loss and reduce negative impact on patient quality of life.

In addition, Sláintecare and the Primary Care Eye Services Review Group Report contains plans for the roll out of personalised and community-based Primary Eye Care Teams aiming to deliver high quality, safe and consistent services for patients within the community and reduce the burden within the acute setting, leading to improved and timely access to supports [13].



Recommendations

There is a critical need to raise greater awareness of AMD and the importance of regular eye checks, particularly for people over the age of 50.

This research highlights the necessity for the implementation of the recommendations outlined in the Primary Care Eye Services Report (2017) to move the point of care for appropriate conditions, such as wet AMD, out of acute hospitals into primary care settings in the community. This will lead to improved access to diagnosis and treatment for patients in their communities and alleviate pressure on acute centres while reducing the travel burden on this older patient group.

In addition, an agreed set of timelines should be developed akin to the clinical programme for the management of Diabetic Macular Oedema (DME), a form of diabetic retinopathy, which has been successfully rolled out in Ireland for patients with diabetes to guide the management of the condition. DME, like wet AMD, is one of the largest causes of sight loss but within the working age population and follows a similar treatment plan.

The Irish Government needs to develop guidelines in line with the UK derived NICE Guidelines for late AMD [14] (the term used to describe wet active AMD), which recommend the following timelines:

3. 1-day referral to a hospital-based macular service from general ophthalmology or other healthcare professionals such as GPs and optometrists;
4. 14 days for treatment from referral date if 'wet active' AMD is confirmed.

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