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COMMENTARY

Expert Consensus on Geographic Atrophy in the EU: A Call for Urgent Policy Action

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ABSTRACT

Geographic atrophy is an eye disease that greatly interferes with the daily lives of patients and their families, posing a serious threat to the aging European demographic. Over the past 30 months, this initiative has assembled leading experts in the field of ophthalmology to share insights on the necessary policy steps that need to be taken to overcome this challenge on an EU-wide scale. Through analyzing best practices in Germany, Italy, France, and Spain, this consensus paper sets out a series of policy recommendations, which, if implemented, could greatly benefit all individuals affected by geographic atrophy. Amongst other features, these countries have provided valuable examples of awareness campaigns and an overall commitment to inclusive and comprehensive policies. The policy recommendations emerging from this paper include the adoption of comprehensive screening programs, retinal disease screening in the EU Driving License Directive, the development of a white paper at the European Commission, and the creation of Council recommendations on eye health screening. Given the significant improvements made at the national level throughout the EU, countries will

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The paper was developed by RPP Group and a group of independent experts (physicians and patient advocates).

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require unitary support at the European level to further develop their policies and successfully address the burden of geographic atrophy.

Keywords: Europe; Geographic atrophy; Retina; Screening

Key Summary Points

From a comprehensive evaluation of Germany, Italy, France, and Spain, this paper underscores the collective progress and challenges in addressing visual impairment, particularly age-related macular degeneration (AMD) and geographic atrophy (GA), emphasizing the need for ongoing improvements and collaborative efforts.

Launched in November 2022, the policy recommendations discussed in this paper advocate for strategic measures, including comprehensive vision screening programs, retinal disease screening for elderly drivers, and a White Paper on Ageing, to address the specific challenges faced by elderly adults.

With a focus on European collaboration, the proposed actions extend to the creation of Council Recommendations on Eye Health Screening and the establishment of GA registries, aiming to enhance standardized screening programs and bridge the existing data gap on GA prevalence.

The national initiatives in Germany, Italy, France, and Spain are acknowledged for their efforts to improve the lives of visually impaired individuals, yet the paper emphasizes the essential need for European-level support to prevent the escalating burden of GA on both patients and society.

Looking ahead, the paper outlines the next steps, involving the development of a campaign manifesto for upcoming EU elections, adaptation of EU policy recommendations to national contexts, and sustained collaborative efforts at both European and national levels to advance GA research, policy, and treatment options.

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INTRODUCTION

Macular degeneration encompasses various eye disorders that affect the macula, the central region of the retina crucial for vision. When affecting individuals over the age of 50, the most common disease is age-related macular degeneration (AMD). AMD is a leading cause of legal blindness in industrialized nations, including two late-staged forms—non-neovascular ("dry") AMD, also known as geographic atrophy (GA), and neovascular ("wet") AMD [1]. While therapeutic options exist for wet AMD, there are currently no available treatments for its dry form, GA, in Europe. Given this lack of treatment for GA, the paper explores how the policy landscape across the EU needs to adapt in order to prepare health systems for when treatment becomes available. While many national initiatives focus on wet AMD due to the fact that treatment exists and therefore engagement on the subject matter is higher, the central subject throughout remains to be GA.

Unlike wet AMD, which typically causes acute vision loss, GA is a progressive disease that leads to irreversible vision loss over time. It currently affects almost 5 million people

worldwide, a number which has been projected to rise to 10 million by 2040, especially due to an aging population [2].

GA interferes with daily activities such as driving, reading, writing, and recognizing faces, significantly impacting patients' quality of life, mobility, autonomy, and independence [3]. Caregivers of people living with GA, despite being commonly perceived as individuals not impacted by the disease, share the financial and mental health burden, often receiving limited support and guidance [4]. Despite its devastating impact and the lack of treatment options, eyecare is not adequately addressed in EU policies or at the national level. Treatment options have started to receive FDA approval in 2023 and certain options are currently being evaluated by the European Medicines Agency (EMA) [5]. In order to ensure the timely detection of the disease and effective provision of treatment for GA if and once available, policies on eye health need to exist to create both patient and medical awareness.

Overview of Initiative to Date

For the past 30 months, a group of experts from the ophthalmological field, as well as patient advocate representatives from Germany, Italy, France, and Spain (hereafter referred to as 'EU4'), have collaborated to raise awareness of the urgent need to update EU policies to include eye health in general, as well as specifically adjusting policies to create a favorable environment for patients living with GA. This joint collaboration came to a culmination in November 2022, in which policy recommendations on GA were officially launched in the European Parliament [6].

The recommendations are informed by expertise from contributors from the EU4 and provide concrete best practice examples from these countries. The document provides a detailed introduction to GA, addresses the burden of the illness on patients and their caregivers, the importance of early diagnosis (how this can be facilitated and the outcomes that can be achieved), the socio-economic impact of GA, which ranges from healthy aging to occupational health and safety, to the economic burden; and finally concrete suggestions as to how healthcare systems in the EU can be adapted and sufficiently prepared for treatment options currently in development.

Culmination of Work Through Launch Event of Recommendations in the European Parliament

In November 2022, Belgian Member of the European Parliament (MEP) Pascal Arimont from the European People's Party (EPP) hosted an event in Brussels launching policy recommendations addressing GA. These recommendations have gained endorsement from ten MEPs representing five different countries and four political groups of the European Parliament, signifying a noteworthy achievement as GA is being addressed at the European level for the first time.

The focal point of the launch event revolved around a panel discussion, where representatives from the European Parliament and the European Commission engaged in a constructive exchange of perspectives with patient advocacy groups, caregivers, industry stakeholders, and medical experts specialized in ophthalmology. Further attendees included representatives from national health institutions, such as ministries of health, as well as figures from organized civil society groups actively engaged in promoting eye health and healthy ageing.

The collective aim of this panel was to establish a comprehensive and pan-European approach to eye health, specifically focusing on GA, with the ultimate objective of enhancing the quality of life and well-being of patients and their caregivers. The launch event marked a significant milestone in calling to attention the need to prioritize eye health within the EU's policy agenda. It served as a platform for informed discussions and the exchange of views among the attendees and was the first of its kind to address GA at the European level.

The discussions during the event highlighted several key points. Firstly, there is a pressing need for policy support and dedicated resources

to address the substantial unmet medical needs of patients with GA. Participants emphasized the need for integration of eye health into the broader EU policies, particularly within the context of healthy and active ageing. By recognizing the demographic changes and the European aging population, measures must be implemented promptly to ensure the autonomy and independence of the elderly.

Medical experts underlined the existing disparities in treatment options for patients with neovascular AMD vs. patients with GA lacking approved treatments. The challenges faced by patients and caregivers were also discussed extensively, highlighting the loss of independence and mental health burden imposed upon patients. Additionally, the unique needs of caregivers were acknowledged, calling for the provision of legal status and support to alleviate their burdens.

The European Commission expressed its commitment to engaging with stakeholders through platforms such as the EU Health Policy Platform and the Best Practices Portal. While acknowledging its limited prior experiences in the field of eye health, it called for the sharing of best practices in health promotion, prevention, and the management of non-communicable diseases (NCDs). This collaborative approach aims to develop evidence-based strategies to address challenges posed by diseases such as GA.

The insights gleaned from this event provide a valuable foundation for developing evidence-based strategies to tackle GA and improve the well-being of patients and their caregivers.

This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

THE STATE OF PLAY OF GEOGRAPHIC ATROPHY IN THE EU 4

Despite acknowledgement of the importance of screening for retinal diseases, most countries in Europe still lack nationwide programs for retinal disease screening. The following section will provide a comprehensive overview of the approaches towards healthy aging and eye examinations adopted at the national level of the EU4 (Table 1).

Germany

In Germany, an estimated 7 million people currently live with AMD, of which approximately 400,000–450,000 live with GA [7]. According to the Eye Doctors Association of Germany (BVA), approximately 100,000 Germans are registered as legally blind, of which GA is a leading cause [8].

There are several patient and stakeholder organizations across Germany that aim to improve and facilitate the lives of those affected by visual impairment. Some of these include AMD-Netz, a network of experts in the field of AMD. Behind it is a registered association that was founded in Münster in 2011, and since then, ophthalmologists, optometrists, counseling centers, support groups, rehabilitation teachers, government institutions, and professional associations across the country have been working to preserve the quality of life for those affected [9]. Patient organizations include Pro-Retina e.V, *Christoffel Blindenmission,* German Association for Legally Blind and Visually Impaired Persons (*Deutscher Blinden- und Sehbehindertenverband (DBSV)*), German Committee for the Prevention of Blindness (*Deutsches Komitee zur Verhütung von Blindheit*), and the German Society for Blind and Visually Impaired for Students and Professionals (*Deutscher Verein der Blinden und Sehbehinderten im Studium und Beruf e.V. (DVBS)*). These nationwide organizations engage in initiatives such as Week of Vision (*Woche des Sehens*) that aid in the overall well-being of affected individuals and provide a platform for public awareness and inclusion. Such initiatives include online simulators designed to emulate the daily challenges visually impaired persons face. The General Legally Blind and Visually Impaired Society Berlin (*Allgemeiner Blinden- und Sehbehindertenverein, ABSV, Berlin*) offers a general simulator [10] while the Week of Vision offers a more specialized Train [11] and Bus simulation [12].

Table 1 Summary of country specific eye health data and eye health initiatives

Country	Summary
Germany	Estimated 7 million people with AMD, 400,000–450,000 with GA
	Various patient and stakeholder organizations (e.g., AMD-Netz, ProRetina) working to improve lives
	German Ophthalmological Society (DOG) promotes research and education on AMD
	German government appointed a Commissioner for Disabled Persons and passed the Federal Participation Act in 2020
	Challenges in accessing adequate services for visual impairment, especially in policy and political spheres
Italy	10.4% of the population suffers from vision loss
	Numerous patient, medical, and professional organizations (e.g., UICI, IAPB, SOI) working towards improving eye health
	Patient organizations like Comitato Macula and Retina Italia ODV actively involved in awareness campaigns and support
	"Healthy Eyesight" campaign aims to spread awareness and provide solutions for visual impairments
	Government initiatives like "Bonus View" providing financial support for prescription glasses
	National Plan for Chronic Diseases does not recognize macular diseases
France	AMD affects around 8% of the population
	French Health Authority emphasizes the need for earlier detection of AMD
	Challenges in constructing a structured care pathway and administrative recognition of AMD as a long-term condition
	Association DMLA is a leading national association dedicated to AMD
	Legislative policies like the Social Security Financing Act for 2023 introduce prevention appointments
	Limited efforts in protecting patients with AMD and informing the public, but recent initiatives are promising
Spain	Spain has the highest visual loss rate in Western Europe (19% in the over-50 population)
	Approximately 800,000 people over 65 suffer from AMD
	Government approved a National Plan for Visual Health and Prevention of Blindness in response to initiatives by Macula Retina
	Organizations like Asociación Acción Visión España (AVE) and ONCE support visually impaired individuals
	Lack of public awareness in Spain regarding eye diseases and visual loss
	Ongoing negotiation for a nationwide plan to improve prevention, diagnosis, and treatment of visual pathologies

AMD age-related macular degeneration, *GA* geographic atrophy, *UICI* Italian Union of the Blind, *IAPB* International Agency for the Prevention of Blindness, *SOI* Italian Society of Ophthalmology, *ONCE* Spanish National Organization of the Blind (Organizacion Nacional de Ciegos Espanoles)

Turning to medical societies, the German Ophthalmological Society *(Deutsche Ophthalmologische Gesellschaft (DOG))* plays a significant role in promoting research, education, and professional standards in ophthalmology, including for AMD treatment. Their campaign "Ophthalmologists inform: Age-related macular degeneration" (*Ihre Augenärzte informieren: Die altersabhängige Makuladegeneration*) provides general and technical information on AMD, that is easily accessible to the public [13]. In addition, the Foundation of the DOG ("Stiftung Auge") has recently launched a nationwide awareness campaign specifically addressing AMD. Furthermore, the DOG provides relevant guidelines on the protection and well-being of visually impaired persons (Guideline 7—Care of the visually impaired) [14], and AMD in particular (Guideline 21—Age-related macular degeneration) [14].

The German government has demonstrated a proactive approach in engaging with visually impaired persons. In May 2018, the Federal Government appointed Jürgen Dusel, a German lawyer who has been legally blind since birth, as Commissioner for Disabled Persons. Under his auspices in 2020, the German government passed the Federal Participation Act (*Bundesteilhabegesetz (BTHG)*), a comprehensive package of laws that will come into effect in four staggered reform phases by the end of 2023 and includes many improvements for people with disabilities, including creating more opportunities for participation and self-determination for people with disabilities [15].

The BTHG has created more opportunities for participation and more self-determination for individuals with disabilities. It grants people with disabilities receiving integration assistance the ability to keep more of their income and assets. At the same time, the burden on the municipalities and counties is reduced, as basic income support and integration assistance is no longer a prerequisite.

The German Ophthalmological Society (DOG) and the Eye Doctors Association of Germany (BVA) have issued a corresponding statement on the quality assurance of optical coherence tomography (OCT). OCT is an imaging technique based on the use of low-coherence light to capture two- and three-dimensional images of the retina [16]. Since October 2019, based on a decision of the Federal Joint Committee (G-BA) from December 2018, the use of OCT for the diagnosis and monitoring of intravitreal injection treatment (IVOM) in wet AMD and diabetic macular edema (DME) has become a standard benefit of the statutory health insurance funds. The G-BA is the highest decision-making body of the joint self-government of physicians, dentists, psychotherapists, hospitals, and health insurance funds [17]. For this purpose, corresponding fee codes have been defined in the uniform valuation standard (*Einheitlicher Bewertungsmaßstab (EBM)*) by the evaluation committee consisting also of representatives of panel doctors and health insurance funds [18].

Despite all these efforts, however, patients continue to experience issues and obstacles securing a doctor's appointment with a specialist who can effectively detect GA. Despite doctors' recommendations to include a screening for AMD/GA for patients past the age of 65, and OCT being able to detect GA, doctors and above all patients in Germany are in general disincentivized to perform a screening for GA as the service is not covered by the standard reimbursement catalogue.

Overall, although, as explored above, there is evidence that Germany has engaged in providing support and facilitating the lives of these patients, challenges remain when it comes to accessing adequate services to support visual impairment, especially in the policy and political sphere.

Italy

As of 2020, 10.4% of Italy's population suffered from vision loss, around 6.3 million individuals, of which 108,853 are registered as legally blind [19]. Alongside Spain, Italy ranks among the worst affected countries in Western Europe for vision loss prevalence with countries such as Portugal, France or Austria scoring 7.4, 6.5, and 6.6%, respectively [20]. From research conducted on the global prevalence of late and dry AMD, we can estimate that the prevalence of

late AMD in Italy affects around 220,000 patients, while approximately 170,000 patients suffer from dry AMD [21, 22].

Italy ranks high in terms of its response towards the issue of vision loss. Nearly 120 ophthalmologists per million are available to the Italian population, ranking it eighth worldwide [22]. Yet a problem the nation has seemed to face is the lack of awareness for eye diseases across the Italian population. In a study conducted in the Abruzzo region, this lack of awareness became apparent; 78% of test subjects were unaware they were suffering from cataracts, 93% did not know they had macular degeneration, and 100% of tested individuals were unaware they had retinopathy [23].

Despite this lack of awareness, Italy has many patient, medical, and professional organizations which work towards improving eye health in the country.

The oldest organization in Italy that represents and protects the moral and material interests of visually impaired people is the Italian Union of the Blind (UICI), founded in 1920 [24]. Additionally, the International Agency for the Prevention of Blindness (IAPB) is active in advocating for visually impaired persons and providing public awareness on the matter. Founded in 1975, it is intended to act as a coordinating umbrella organization to lead international efforts in vision loss prevention activities. Its main goal is to promote and strengthen the global campaign against all forms of visual loss, with a specific focus on low-income communities [25]. Medical societies such as the Italian Society of Ophthalmology (SOI) [26], the Italian Association of Ophthalmologists (AIMO) [27], and the more recently founded, but already well established, Italian Society of Ophthalmological Sciences (S.I.S.O), [28] play a crucial role, serving as a reference point for ophthalmology in the country. They address the challenges faced by the ophthalmological sector in Italy and create a unified platform that represents and serves ophthalmologists of all categories while fostering professional coexistence and meeting industry expectations.

Italy boasts numerous patient organizations representing the interests of patients and their caregivers. The non-profit association Comitato Macula, for example, represents patients with maculopathies, and works towards seeing their rights recognized, campaigning for better diagnosis and treatment options as well as promoting knowledge and research in the area of ophthalmology. They are active in producing awareness campaigns such as their initiative 'Testalavista', providing free visual screenings for local communities, and being a voice for patients at the national and European levels [29]. Retina Italia ODV is the National Association against inherited retinal dystrophies and other retinal diseases including age-related macular degeneration. The association has offices across Italy and is active in nearly all regions. To fulfil its aim of promoting research to find a cure for retinal dystrophies, Retina Italia ODV funds scholarships for young professionals such as biologists, orthoptists, and geneticists, and funds scientific research projects. Furthermore, Retina Italia ODV aims to inform patients about scientific research, the availability of visual aids, and developments in national law regarding the well-being of visually impaired persons [30]. To do so, Retina Italia ODV publishes LUMEN, a quarterly magazine for updates and information on low vision, its causes, and its social and labor impact. Further, the association provides a weekly e-mail newsletter called Retinaflash to update its audience on the latest scientific news and activities of the association [31]. It is encouraging to see that more patient organizations are cropping up in Italy, such as the Association of Patients of Eye Diseases (APMO), which is a relatively new national patient organization dedicated to promoting rapid diagnoses and providing patients with retinal diseases and glaucoma with high-quality and rapid services and treatments [32]. Such continued establishment of patient organizations is a reflection of the dedication of stakeholders in the country to work towards improving the lives of patients living with visual impairment.

One successful awareness-raising and screening campaign is "Healthy Eyesight" (Vista in salute), a mobile screening project funded by Law 145, December 30, 2018, aiming to provide solutions to problems around visual

impairments, in particular the early diagnosis of retinal diseases. In its initial phase in 2021, the campaign was limited to the Umbria region. In 2023, however, the campaign has evolved into a nationwide operation. It focuses on three main pillars and objects, namely (1) to spread awareness about the main eye diseases that cause visual impairment or blindness, (2) to increase the level of priority given to eye health prevention in regional health agendas, and (3) to use collected data to implement a national database, providing vital tools for the development of public health policies for the promotion of eye health. This involves regular, free eye tests available to the public. The project has received the patronage from multiple institutions, including the Ministry of Health, the State-Region Conference, the National Health Institute, the National Association of Italian Municipalities (ANCI), the Umbria region, the Italian Union of the Blind and Visually Impaired, as well as the Interparliamentary Group for the Protection of Sight, the latter of which was launched in May 2023 [33].

The Ministry of Health also directly engages in campaigns and programs to facilitate the lives of those affected by visual impairment diseases. "Bonus View" (*Bonus Vista*) is an initiative endorsed by the Ministry of Health that provides a contribution of €50 to individuals for the purchase of prescription glasses or corrective lenses [34]. Individuals from low-income households are particularly affected by visual impairment diseases. This initiative provides these individuals with the opportunity to afford high-quality glasses, facilitating their everyday lives.

In 2016, the Italian Ministry of Health published a National Plan for Chronic Diseases. This plan aimed to improve the protection of individuals with chronic diseases, reduce the burden on the individual, their family, and the social context, enhance the quality of life, make healthcare services more effective and efficient in terms of prevention and care, and ensure greater consistency and equity in citizen access [35]. To date, however, this plan unfortunately does not recognize macular diseases as chronic diseases, meaning these patients cannot benefit from dedicated diagnostic and therapeutic pathways being set up.

While Italy has made significant efforts to address the issue of vision loss, with numerous medical and patient organizations, awareness campaigns, and government initiatives in place, there are cases highlighting the need for continued action to improve early diagnosis, treatment options, and support for individuals with visual impairment diseases.

France

In France, AMD is the leading cause of visual impairment after the age of 50 [36]. It is estimated that the disease affects around 8% of the French population, with the incidence increasing significantly with age: it affects 1% of people aged 50–55, around 10% of people aged 65–75 and 25–30% of people over 75 [37]. In terms of the advanced form of the disease, associated with a loss of central vision, these figures can be reduced by around half. While no exact figures exist on the prevalence of GA in France, we can estimate that there are around 265,000 patients with the illness based on research conducted by Rudnicka et al. [38], Awareness of the disease has improved over the past decade thanks to information campaigns: in 2012, 50% of the over-50s were aware of AMD, compared with just 3% in 2007 [39].

The French Health Authority (*Haute Autorité de Santé (HAS)*), the leading health authority in France, updated its recommendations for good practice in October 2022, stressing the need for earlier detection of AMD [40]. Once AMD causes visual impairment, the HAS recommends that patients be offered low-vision rehabilitation to encourage independence and develop strategies to compensate for the loss of vision. It specifies that patient care must be multidisciplinary and may include a wide range of professionals: ophthalmologists, general practitioners (GP), orthoptists, opticians, and, depending on the case, occupational therapists, physiotherapists specializing in mobility and activities of daily living, psychiatrists, psychologists, psychomotor therapists, social workers, and patient associations [40].

Despite these recommendations, the main challenges concerning AMD are the construction of a structured care pathway to provide comprehensive care for these patients and recognition of the disability from an administrative perspective. For example, AMD is not recognized as a long-term condition (*Affection Longue Durée (ALD)*) by social security organizations, meaning that transport costs are not covered.

Regarding associations and organizations in France, the 'Association DMLA' is the leading national association exclusively dedicated to AMD. It not only aims to inform and support people with AMD and their families, but it also supports medical and scientific research on AMD. The initiatives comprise a toll-free helpline for patients seeking support and advice, the distribution of a quarterly newsletter, and informative sessions conducted by trained volunteers.

Additionally, France has implemented legislative policies, such as the Social Security Financing Act for 2023, adopted by the National Assembly on December 23, 2022, which outlines the introduction of 'prevention' appointments for people that reach specific ages [41]. These prevention appointments, reimbursed at 100% by the French health insurance system, may involve prevention consultations and information, health education, health promotion and prevention sessions. Their objectives are to promote physical activity, sport and a healthy diet, to prevent cancer, addiction, and infertility, and to promote mental and sexual health. They must also take into account women's health needs and detect the first signs of age-related fragility with a view to preventing loss of autonomy. As the specific use and function of these appointments have not yet been determined, this offers an opportunity to voice the importance of screening for age-related diseases, such as eye diseases, specifically AMD and GA.

Even though AMD affects a significant portion of the French population, France's efforts in protecting patients with AMD and informing the public remain relatively low. Few organizations and associations exist, making access to information difficult, while patient pathways are also a cause for concern. However, the recent initiative by the French Health Authority and the potential envisaged by the Social Security Financing Act are promising.

Spain

Alongside Italy, Spain suffers from the highest rate of visual loss compared to other Western European countries. With a visual loss prevalence of 19% in the over-50 population, it ranks highest amongst Western Europe [42]. This poses a threat to the currently aging population, particularly given that Spain has one of the highest percentages of elderly people in the world [43]. Approximately 800,000 people over the age of 65 suffer from age-related macular degeneration, an estimated 155,000 with GA/AMD [44] with around 71,000 people registered as legally blind [45]. In 80% of the cases of wAMD, diseases and symptoms are preventable if diagnosed and therapeutic intervention were available to individuals [45]. In one of the most recent national studies, the overall prevalence of AMD was 7.6%. The prevalence of early, intermediate, and advanced AMD (wet and dry) was 2.9, 2.7, and 2.0%, respectively [46]. Of the 9129 AMD subjects, 1161 (12.7%) had geographic atrophy [46]. In recent years, the government and two associations, namely the Macula Retina Association (Asociación Mácula Retina) [47] and the Spanish National Organization of the Blind (*Organizacion Nacional de Ciegos Espanoles (ONCE)*), have led initiatives to curb the worsening trend and improve the quality of lives of those affected [48].

On April 21, 2021, the government approved a request by the senate under the proposal of the Association of Patients and Relatives Macula Retina, to develop a National Plan for Visual Health and Prevention of Blindness[49]. Following its approval, the Health and Consumer Affairs Commission of the Upper House urged the government to develop strategies in research, economic sustainability, organizational modeling, and social legitimation for individuals suffering from visual impairments. Further, it requested the central government to

implement the necessary measures to improve the prevention, diagnosis, and treatment of different visual pathologies. Approximately 11 months later, on March 22, 2022, the regional parliament of Navarra initiated the motion to pioneer the development of a national plan [50]. The regional parliament is currently studying an initiative that focuses on early diagnosis, research and resources which can serve as a roadmap for the implementation of a plan at the national level [50]. The blueprint for a national plan, that most likely be applicable in all regions of Spain if approved, is currently in its negotiation phase with a publishing date yet to be announced.

Aside from the Ministry of Health and Macula Retina, an influential organization that supports people with visual impairment in Spain is Asociación Acción Visión España (AVE). AVE emerged through the consolidation of multiple entities specializing in studying low vision-related pathologies, all sharing common characteristics, areas of operation, and goals. The non-profit organization support people affected by different visual pathologies who have low visions, as well as their families and caregivers, and offers guidance on the most suitable entity or entities, categorized by pathology or geographic region, to provide patients with optimal services [51].

Another important organization is ONCE, an organization which aims to protect the interests of visually impaired people in Spain. Founded in 1938, ONCE is one of the oldest patients' associations in Spain that aims to improve the lives of blind people, people with visual loss, and people with visual disabilities. Currently, ONCE has 72,000 members. The organization offers a range of assistance programs and benefits to ensure the wellbeing of its members [52]. Such assistance includes providing essential needs in the home, tele-assistance services to meet a patient's needs, or organizing 'social vacations' for both adults and children to ensure the integration of persons with visual impairments.

In terms of public awareness, Spain hosts the International Conference on Retinoblastoma and Retinal Disorders, hosted by the World Academy of Science, Engineering and Technology. This event occurs almost monthly and provides a platform to discuss the most recent developments in the field of eye health amongst healthcare professionals [52]. Despite being available to the public, however, it receives little attention from the general public and receives little coverage. Public awareness in Spain of eye diseases and visual loss seems low and requires improvement.

Spain is amongst the worst affected countries in Western Europe in terms of visual loss prevalence. The lack of initiatives by the government and an absence of proactive initiatives by associations and organizations has resulted in a nationwide issue that will require a unified and strategic approach.

KEY RECOMMENDATIONS FOR ACTION

The evaluation of Germany, Italy, France, and Spain reveals that progress has been made in addressing visual impairment, with each country demonstrating efforts in different domains. Yet, there is still work to be done, with room for improvement to further develop GA awareness and support measures across Europe, including in the EU4.

Each country possesses noteworthy attributes in advancements towards treating GA. Germany's differentiation lies in its collaborative approach and implementation of legislative measures, which underscore the crucial significance of stakeholder cooperation. Italy's exemplary focus on awareness and prevention initiatives presents a valuable model for other nations to emulate. France's commendable network of organizations and medical societies serves as a prime example of the vital role played by collective support systems in addressing visual impairment. Spain's dedication to inclusive policies and comprehensive programs demonstrates a strong commitment to ensuring accessibility and equity for all individuals.

However, it is essential to acknowledge that all four European countries continue to face challenges in the eye health arena, such as treatment opportunity, public awareness, and

timely access to specialized care. Thus, continued efforts and targeted improvements are necessary to further enhance the provision of eye health services and ensure the well-being of visually impaired individuals in these countries and those who care for them.

The policy recommendations on GA, launched in November 2022, bring attention to specific actions that need to be implemented to ensure patients receive essential care and support, and ensure healthcare systems' preparedness so that patients can effectively access treatment once it becomes available in Europe. In the following section, this paper reiterates and contextualizes some of these recommendations within the national efforts assessed throughout the evaluation.

Introduction of Comprehensive Screening Programs to Understand Disease Prevalence and Ensure Early Treatment Options

Building on the efforts of Germany, Italy, France, and Spain to provide patients with better access to eye care, it is recommended that European countries introduce comprehensive vision screening programs. These programs should encompass a range of eye conditions, including GA, AMD in general alongside and other retinal diseases, to better understand disease prevalence across Europe. Through early detection and diagnosis, these programs can facilitate timely interventions and ensure that suitable treatment facilities and services are available to address the needs of affected individuals to provide favorable visual outcomes. Collaborative initiatives should be encouraged to harmonize screening protocols, facilitate data sharing, and promote best practices among countries.

Inclusion of Retinal Disease Screening in Driving License Directives for Elderly Adults

European countries should call for the inclusion of retinal disease screening, specifically GA, in the ongoing revision of the Directive on Driving Licenses. This screening should be targeted at individuals aged 60 and above, aiming to identify potential visual impairments that could affect driving abilities. Establishing guidelines and standards for periodic screening would contribute to road safety and enable early interventions to prevent accidents caused by undetected vision impairments.

Development of a White Paper on Aging with a Vision Health Perspective

Taking inspiration from France's Social Security Financing Act for 2023 (the introduction of prevention appointments for people reaching a specific age, reimbursed at 100% by the French health insurance system), the European Commission should develop a comprehensive White Paper on Aging that integrates a vision health perspective. This white paper should recognize the critical role of vision health in healthy aging and outline strategies to address the specific challenges faced by elderly adults. By incorporating preventative measures, early detection, access to specialized care, and rehabilitation services, the white paper should serve as a roadmap for promoting healthy vision throughout the aging process. Collaboration among Member States, patient organizations, and medical societies should be encouraged to ensure a comprehensive and inclusive approach.

Creation of Council Recommendations on Eye Health Screening

European countries should consider the creation of Council Recommendations on Eye Health Screening. These recommendations would provide evidence-based guidelines for standardized and comprehensive screening programs across Europe, addressing various eye diseases and conditions, including GA, wet AMD, retinopathies, and other visual impairments. Drawing on the success of the European Commission's 2003 Cancer Screening Recommendations, as well as the announcement of a revision of these recommendations in 2022, this approach would promote consistency, best

practices, and equity in eye health screening. Regular evaluation and monitoring mechanisms should be implemented to assess the effectiveness of these recommendations.

Improved Data Collection and Work Towards the Development of GA Registries in Europe

As is evident by assessing the state of play in Germany, Italy, France and Spain, there is a lack of data on prevalence of GA across Europe. To enhance the understanding of the prevalence and patients' clinical characteristics associated with GA, European countries should work towards establishing national registries and data collection specifically for GA. These registries should encompass a wide range of essential information, including but not limited to the number of individuals affected by GA, its diagnosis and prognosis and the natural history of the disease. By collecting and analyzing comprehensive data, these registries can help raise awareness, facilitate research, and improve the overall quality of care for individuals with visual impairment.

CONCLUSIONS

Significant steps must be taken at both the European and national levels to effectively address the challenges presented by GA. The recent launch event of policy recommendations in the European Parliament brought together experts, policymakers, patient advocate representatives, and other stakeholders, emphasizing the urgent need for policy support and dedicated resources for patients with GA. The consensus reached during the event highlighted crucial aspects, including the importance of early diagnosis, the unmet medical needs of patients with GA, and the provision of support for caregivers. The event also shed light on the existing disparities in treatment options between wet and dry late-stage forms of AMD, underscoring the necessity for further action.

At the national level, countries such as Germany, Italy, France, and Spain have already implemented various initiatives to enhance the lives of individuals affected by visual impairment and GA. However, these national activities should be recognized and further built upon at the European level, taking into account the key recommendations outlined in this consensus paper. More work, engagement, and cooperation are still required to ensure that patients living with GA are not left behind. Prioritizing nationwide retinal disease screening programs, as well as ensuring access to timely and effective treatments, is of paramount importance.

It is essential to acknowledge the significant progress made at the national level. However, countries require support at the European level to continue building on these achievements and prevent the burden of GA from becoming unmanageable for patients, caregivers, and society. This necessitates maintaining collaborative efforts, engaging stakeholders, and allocating necessary resources to further advance GA research, policy, and treatment options.

Next Steps

The next steps of this initiative will involve the continued work towards implementation of the policy recommendations. This firstly entails the development of a comprehensive campaign manifesto on geographic atrophy specifically tailored for the anticipation of the upcoming EU elections next year. Additionally, the EU policy recommendations are being adapted to the French, German, and UK policy landscape, to ensure continued further improved awareness and support measures at the national level.

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Declarations

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Ethical Approval. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

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