

***'Eyes Right'***

***Preventable Blindness  
White Paper***





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# 'Eyes Right' Preventable Blindness White Paper



## Message from the authors

Eye disease and its prevention is a major issue in Europe today - and will only become bigger as the 500-million-plus population ages (and the incidence of, for example, diabetes grows).

The high fiscal and societal burdens are outlined in this White Paper, along with other pertinent facts and figures, survey results and more.

To support a common effort on behalf of all stakeholders in this area, we have published this White Paper, agreed by consensus, to explain the need for, among other things, a more preventative approach to blindness across the EU's Member States.

Generally speaking, healthcare professionals need to quickly identify high quality, trustworthy clinical practice guidelines and methods, in order to improve decision making for the benefit of their patients.

Meanwhile, patients need to be better informed and screening programmes need to be in place for their short- and long-term benefit.

Research has shown that patient-centred care models are cost-effective and lead to better outcomes and patient satisfaction.

It is clear that in most areas of healthcare, preventative measures need to be boosted across Europe, through better information for patients, broader screening programmes and

improved diagnostic tools that are available to all citizens regardless of where they live and their financial status.

There is, therefore, a definite case for more screening programmes for preventable blindness.

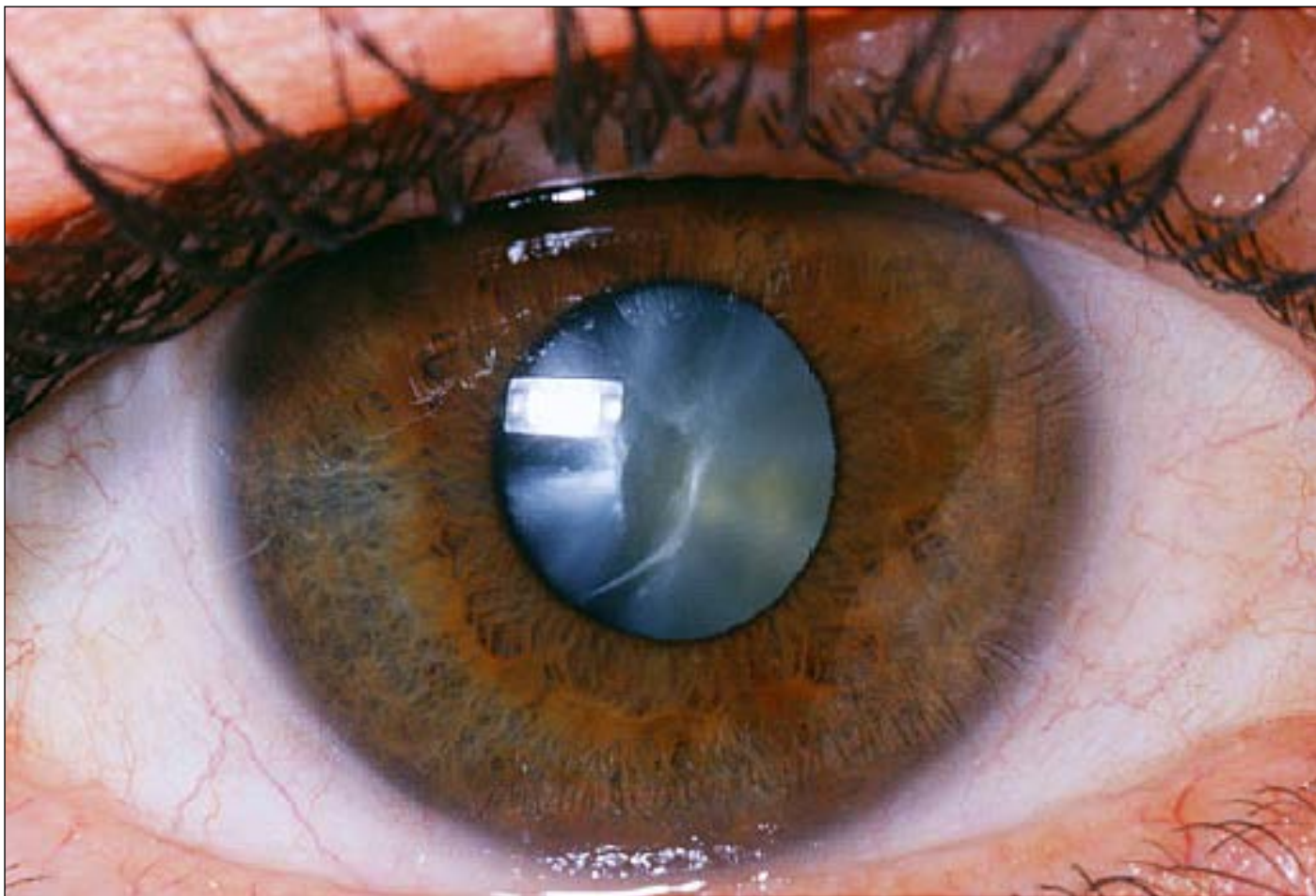
There is also a need for agreement and coordination across the European Union's Member States on this matter.

We are all under no illusions that healthcare is one of the biggest challenges facing Europe today, and can only be improved and sustained with the agreement, cooperation and coordination of all stakeholders.

Key to this is how healthcare is governed in the EU and what influence, in effect, Brussels can and does have, bearing in mind that much of the areas of health come under Member State competence.

New screening programmes and information to prevent avoidable blindness would be one way giant leap forward.

The authors of this White Paper believe that without screening and early detection of preventable eye diseases, leading in the worst-case scenario to blindness, much of the incredible medical science being developed will struggle to fulfil all of its potential, especially when it comes to improving the quality of lives of all of our citizens, now and for generations to come.



## Introduction

The battle against eye disease in Europe needs to be fought at EU level.

Blindness - obviously the worst-case scenario among issues affecting vision - is described by the World Health Organization as: "Visual acuity of less than 3/60, or a corresponding visual field loss to less than 10°, in the better eye with the best possible correction."

'Visual impairment', it says, "includes both low vision and blindness".

There are some 39 million blind people in the world, but 80 per cent of blindness can be cured or prevented. That's 31.2 million people who are blind when they needn't be.

Studies suggest, outlined below, that eye disease costs society in Europe some €20 billion, causing a significant economic burden.

Much of these costs are due to day-to-day care for the blind by relatives and friends. This, therefore, has an impact on society as a whole, not just on the sufferer.

Organisations working in the area, such as the European Forum Against Blindness (EFAB), have highlighted the fact that investment in screening programmes, earlier (and better) diagnoses and adequate treatment of retinal conditions, can lower the economic burden and bring about improved quality of life, and therefore a more productive population. Yet again, 'health means wealth'.

Debilitating sight loss can result from such conditions as cataracts (by far the most common reason), diabetic retinopathy, glaucoma and wet AMD, among others.

Let's take cataracts as an example, here:

A cataract is a clouding of the eye's natural lens, (see above) which lies behind the iris and the pupil. Cataracts are the second leading cause of visual impairment after refractive errors (uncorrected refractive errors such as hyperopia or astigmatism: 43%, cataracts: 33%, glaucoma: 2%). They remain (47.9%) the leading cause of visual impairment in all areas of the world, except for developed countries (WHO).

There are several types, including sub-capsular cataracts at the back of the lens, a nuclear cataract forms deep in the nucleus of the lens, and cortical cataracts.

Cataracts start small and most people don't notice the effect on vision. Occasional blurring or cloudiness may occur, and glare from the sun or a lamp may seem brighter. Colours start to fade.

On the other hand, the sub-capsular version may not even produce any noticeable symptoms until it is well developed.

It is known that cataracts can be caused by a number of issues that include (but are not exclusive to) ultraviolet radiation from sunlight, etc, diabetes, lifestyle issues such as obesity, smoking and high alcohol consumption, hypertension, a prolonged use of certain drugs and, of course, family history - genetics. Prevention here, is clearly possible and desirable.

## Geographic Atrophy (GA)

Age-related macular degeneration (AMD) is one of the leading causes of blindness worldwide. Geographic atrophy (GA) is an advanced form of AMD. It is a progressive and irreversible disease resulting in death of cells in the retina. This results in reduced visual function and people experiencing blind spots, having difficulty reading, recognising faces and doing daily tasks.

Approximately five million people are affected by GA and the incidence increases exponentially with age. In developed nations, GA is estimated to occur in about 3.5% of people over 75, and increases to about 23-35% in those over 90 years old.

There is no known cure for GA and there are currently no approved treatments. Early detection and intervention are key to providing the best possible care for people with AMD and GA. Yet, as it currently stands, there is a huge variation in the detection and treatment of GA worldwide.

Better awareness and education is vital to ensure that people with GA are diagnosed and receive the right care, helping them to manage their condition and maintain their independence for longer, alleviating burden on carers and family members.

What is certain is that cataracts can seriously impede day-to-day living. Left too long, those with cataracts may lose most of their sight, finding it difficult to get around in public (stairs, kerbs, crossing the road at traffic lights as they cannot see the colours in bright daylight) to the point where the daily task of walking can be a dangerous activity at times.

By this stage, stronger glasses (even a magnifying glass) will not help much and the only realistic option is for a relatively simple and painless (if a little uncomfortable) operation.

Cataract surgery is very successful, with 90% of patients regaining good vision, although often reading glasses are needed for close-up work in perpetuity, as the vast majority of replacement lenses are set to a longer distance, for obvious reasons of aiding mobility.

Leaving the particular issue of cataracts aside, when it comes to loss of eyesight, more timely diagnosis, intervention and, at the core, research and awareness of the extent of the problem are key.

The authors of this White Paper are also acutely aware that many diseases and issues affecting eyes are, in fact, genetics based (although, as mentioned, certain factors such as heavy smoking do not help cataracts).

Stakeholders strongly believe that the EU should be doing more to facilitate research and raise awareness of eye diseases, which have a low profile compared to other diseases that ruin the quality of life, on a daily and long-term basis, of sufferers and have a huge impact societally and financially.

Currently, there is far too little awareness to push Europe into tackling this at policy level.

Therefore, the goals of this White Paper include:

- *Helping to raise awareness of preventable blindness in the EU while better informing patients and healthcare professionals on the subject*
- *Promoting policies of screening, early diagnosis and adequate care and treatment across all Member States*
- *Pursuing patients' rights to adequate treatment, safety and informed choice*

One high-profile event in progress for some time is World Sight Day, which is viewed as the most important advocacy and communications event on the eye health calendar.

World Sight Day 2017 will take place on 12 October, under the banner 'Make Vision Count'. It is an annual day of awareness to focus global attention on blindness, visual impairment and rehabilitation of the visually impaired, and was first celebrated in 1998.

Key decision makers, policymakers, government officials, patients, partners/donors and the wider health community (referral networks like diabetes groups, for example) are always invited to participate in World Sight Day, with annual events taking place at the European Parliament, for example.

Speaking of the European Parliament, in the recent past at least one debate has been held in the Brussels seat, featuring MEPs and leading professionals across the field of vision health.

Again, this was primarily to raise awareness about preventable blindness across Europe, and why blindness (and its prevention) should become a public health priority.

Obviously, the problem looks set to worsen as the population of Europe ages, bringing about an added financial burden on society and a sizeable one on healthcare systems everywhere. Prevention is the sensible answer...

## Diabetes and eye problems

Most people know that diabetes often causes problems with the eyes and can lead to total blindness in the worst cases. Sufferers certainly have a higher risk of developing eye problems, although disorders are usually minor. Regular check ups are advised in these cases.

**Prevention to the fore, yet again.**

Experts agree that if problems continue to develop they can usually be solved with early treatment. Once more, early diagnosis and such swift treatment prevents bigger problems down the line.

Diabetes sufferers are 40% more likely to suffer from glaucoma than those without the disease. The longer a patient has had diabetes, the more common glaucoma is. Age, as ever, also increases risks.

Several treatments exist in the event of glaucoma, including using drugs to reduce eye pressure or surgery when necessary.

As noted elsewhere in this White Paper, cataracts are common and, while by no means all cataracts are caused by diabetes, those with the disease are 60% more likely to develop this most common of all eye conditions.

Diabetes sufferers often develop cataracts relatively young in life and problems progress more swiftly in such cases.

Cataracts that interfere greatly with vision usually have the lens of the eye removed, which is replaced with a transplanted lens. In people with diabetes, this can lead to glaucoma developing, for which, as mentioned, there are established treatments.

**Once again, the role of prevention cannot be over-stated.**

Other eye diseases associated with diabetes include retinopathy (disorders of the retina), both non-proliferative and proliferative. Recently, great leaps have been made in the treatment of diabetic retinopathy.

As usual, the faster diagnosis occurs, the greater the likelihood that treatments will succeed. In fact, it is well-worth noting that optimum results occur when the patient's sight is still normal.

### Prevention

The phrase 'prevention is better than cure' is well known. Although often used as a metaphor, its literal meaning has some substance.

If every disease could be prevented before it began, then the improvements in citizens' health would be assured and the savings for healthcare services would be enormous.

Personalised medicine can go some way to achieving this, with genome sequencing having the ability to spot a tendency to develop a certain disease down the line. This can include certain forms of eye problems.

Resources are of course limited in every sphere - every healthcare system in each of the current 28 Member States is struggling to keep pace with the new demographics - and there needs to be a substantial, 'smart' shift in the way these services spend what money they have. Putting more emphasis on preventative measures is one way to do this.

Surely the case for prevention as treatment - as well as treatment as prevention - is now here, if it wasn't already.

When it comes to interventions into eye-sight related issues, one survey concluded that recommended interventions "include anti-VEGF treatment as standard of care for wet AMD, appropriate early detection, prevention and treatment

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options such as screening for cataracts, diabetic retinopathy and glaucoma followed by treatment”.

Early diagnostics obviously have a major part to play and there has never been a better time to grasp opportunities using latest advances in genomic science, and to acknowledge the benefits of screening programmes.

Such earlier diagnostics and earlier treatment have many benefits, among them fiscal, because while cost is a major issue, better diagnostics will ease the burden on healthcare systems.

Screening will allow a more preventative approach, while swift and efficacious treatment means patients are much less likely to require expensive hospital beds and are more able to continue working and contributing to Europe's economy.

This also has a knock-on effect in respect of carers for blind people.

As the population ages the impact of vision loss will grow substantially in the future. As well as the considerable economic burden to society, blindness also imposes physical, social, financial and quality-of-life limitations on individuals, those directly affected, and their carers, family members and friends.

It can be concluded from studies that prevention of blindness and eye disease through investment in cost-effective interventions will lead to a healthier population, which could result in a more sustainable healthcare budget for governments; a healthier workforce

with attendant lower productivity losses; reduced costs and burden to informal care givers; and improved wellbeing, quality of life and productivity for individuals alongside their having longer working lives.

Therefore the prevention and treatment of vision loss should be a public health priority.

Indeed, five years ago, MEPs called for urgent measures to increase eye-care, given that Europe's ageing population plus an associated rise in chronic diseases such as diabetes is likely to cause a speedy increase in citizens having to deal with impaired vision.

The European Alliance for Personalised Medicine, EFAB and partners believe that timely prevention is certainly possible and critical to reducing the growing burden of blindness.

At the time of the MEPs' call, Alliance supporter and MEP Marian Harkin emphasised the need for adequate and systematic screening for blindness at national level. She also said that more cooperation and adequate referral processes between healthcare disciplines was necessary.

Fundamentally, there is a great fear of blindness among the population of the EU, with 53% genuinely worrying about vision loss and blindness in future. This came second only to a fear of losing their memory, and concerned them roughly twice as much as other conditions, such as diabetes.

The issues are huge and it is time for the scales to fall from Europe's eyes.

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## Economic burden

As mentioned earlier in this document, there are some 39 million blind people in the world.

One recent study estimated that (including the 39m classified as blind) 285 million people are visually impaired worldwide.

The number of blind people in the EU population (aged more than 50) is around 1.3 million, with in the region of a further 10 million living with medium-to-severe visual impairment.

Economic consequences of visual impairment in Europe include direct medical costs due to treatment and diagnosis, treatment of potential future health consequences (which includes an increased risk of falls or other accidents), and direct non-medical costs.

Loss of productivity due to an inability to work is also a huge factor, and this often includes the patient's carer.

These substantial costs are more than likely to increase in the future and much better use of available cost-effective prevention and treatment tools would reduce the burden.

In Europe, partially sighted people outweigh the blind by a ratio of four-to-one and, added together, the average unemployment rate is in excess of 75%, with more women unemployed than men. The latter finding dovetails with the fact that women are more at risk of becoming blind or partially sighted.

In many cases, sight loss is closely related to ageing, with one-in-three citizens facing sight loss above the age of 65. With the population ageing as it is and has been, this has resulted in 95% of the visually impaired being over that age.

As we know, some types of vision loss are called 'preventable blindness'. Much research from various organisations has been undertaken on the cost of blindness in the EU, with all concluding that it is substantial.

Further conclusions state that a broader use of already available cost-effective treatment and prevention plans should reduce the burden substantially.

There is clearly a need for comprehensive eye care for every citizen where necessary in order to reduce the costs associated with blindness and other problems with vision.

One survey was undertaken relatively recently to assess the economic impact and burden of four eye diseases and blindness in six European countries. The countries chosen were France, Germany, Italy, Slovakia, Spain and the UK.

The survey also took into account the cost-effectiveness of interventions to prevent the specific eye diseases.

The burden of disease analysis included both "direct costs", which are all healthcare costs as a result of treatment (including costs of hospitalisation, general practice services, and medications), and "indirect costs" - all costs related to loss of productivity and informal care costs.

For the cost-effectiveness analysis, World Health Organization methods were used to establish whether interventions are worth their investment.

For blindness alone across the six chosen countries, the estimated cost is €7bn annually, while day-to-day care for those suffering from blindness account for the rest of the associated costs.

The study concluded that the best way to offset the total EU burden of €20bn is to build a comprehensive intervention plan.

A further study, with the addition of five more countries - Denmark, Ireland, Poland, Sweden and Switzerland - concluded that blindness and the targeted four eye diseases bring about a significant reduction in wellbeing, and this equates to some 123 million workdays lost every year.

Among other factors, decreasing the cost will necessitate eye-care professionals educating the public about at least four of the main conditions leading to blindness in the EU. As mentioned in the introduction, these are cataracts, diabetic retinopathy, glaucoma and wet AMD.

As such conditions progress towards blindness, the cost of informal care provided by relatives and friends inevitably rises. Therefore, early detection and treatment lowers the likelihood of permanent loss of vision while also bringing down the financial and societal burden.

On top of the fact that there is a need for coordinated screening processes, there are other gaps. For example, current data protection rules in the EU impede the seamless access to medical data that is crucial for both prospective and retrospective medical research.

The EU's Cross-Border Healthcare Directive highlighted inequalities in patient access from country to country. Sometimes these result from inadequate national budgets, thus patients are deprived of new treatments and/or screening for reasons of finance.

The true value of prevention and treatments is too often



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ignored. Patients are too frequently excluded from critical aspects of the discussions on preventable blindness/ screening and choices surrounding treatment - and even when they are invited, they are often marginalised, as the agenda is already fixed by others.

Their perspectives on ethics and risk-benefit are largely neglected in assessment processes.

Patients also have little or no say in long-term budget planning or in discussions of pricing and reimbursement of treatments.

Member States and the EU institutions should act together to overcome the barriers to innovation, including recognising the real value of preventing blindness through screening programmes and making access to them easy, boosting research across Europe generally, and including all stakeholders – and particularly patients – in policy formation.

## An agenda for change

### Easing access to prevention and innovative treatments

Budget planning is required for blindness prevention. The EU and Member States need to prioritise funding for treatment, based on dialogue between opinion leaders in the medical professions, commercial and academic research, and paying agencies.

Greater coordination of product assessment is essential to eliminate anomalies in reimbursement and prescription and to achieve greater alignment in access to preventative treatments across the EU.

Greater transparency and flexibility is needed in pricing and reimbursement of treatments, with the involvement of all stakeholders – not just researchers, industry, payers and policymakers, but also patients.



The evaluation of the cost and benefit of screening and treatments should include a discussion of their value for society. The patient view of value should be given greater weight in assessments, and quality-of-life measures need to be adapted to reflect real value added by early treatment and preventions as experienced by patients.

Generally speaking, cross-border healthcare should be implemented much more efficiently than it has been thus far to make good its promise of better access to healthcare for EU citizens and greater cooperation between Member States. The gaps created by differing national reimbursement systems need to be filled.

### Promoting research into blindness

Research into the causes of cataracts and other eye diseases needs boosting, with platforms for effective collaboration between academia, industry and healthcare systems.

Because limited resources and patient numbers often make it difficult for research to be conducted in all countries, sharing of knowledge and expertise is vital to attain a critical mass of research efforts. A better structure of research and a plan for coordinated screening programmes is needed within the EU.

The European Commission should allocate long-term funds for the prevention of blindness, with increased investment in European research centres, and with advanced databases of biological and clinical data and clinical databases for outcomes research.

Patient registries and databases are essential to permit the pooling of data needed to achieve a sufficient sample size for clinical research. Regulations need to be adapted to allow more sharing of patient data and biological materials.

### Including patients in preventable blindness policy formation

Empowerment and involvement of patients and patients' organisations would enrich reflection on how to tackle preventable blindness. They should be allowed to contribute to shaping an adequate comprehensive European response to eye diseases, and screening programmes, and be given access to the information they need to perform this role.

The WHO defines patient empowerment as a 'prerequisite for health' and encourages a 'proactive partnership and patient self-care strategy to improve health outcomes and quality of life among the chronically ill'.

In this context, eye-patient organisations are crucial in direct support to individuals and in their collective work in improving conditions for current and future patients.

Patients should be entitled as individuals to a voice in the choice of treatment and care that they are offered. Patients should have their rights to information respected, with access to centralised information about services and care nationally and around Europe (preferably in their own language), including about the best possible treatment pathway at different stages, and to help them make informed choices about which treatment and when.

Patients' representatives should also be allowed input into discussions of long-term budget planning.

Efficient and effective action for prevention of blindness depends on a coherent European strategy, and a common approach to mobilising and integrating scarce and scattered resources.

This White Paper calls for urgent EU-wide action, based on all of the above.

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## In brief: Ten things you should know...

- There are some 39 million blind people in the world, but 80 per cent of blindness can be cured or prevented. That's 31.2 million people who are blind when they needn't be.
- Studies suggest that eye disease costs society in Europe around €20 billion, causing a significant economic burden. One recent report estimated that (including the 39m classified as blind) 285 million people are visually impaired worldwide. The number of blind people in the EU population (aged more than 50) is around 1.3 million, with in the region of a further 10 million living with medium-to-severe visual impairment.
- Organisations such as the European Forum Against Blindness and the European Alliance for Personalised Medicine say that investment in screening programmes, earlier diagnoses and adequate treatment of retinal conditions, can lower this economic burden and bring about improved quality of life.
- Comprehensive screening will allow a more preventative approach, while swift and efficacious treatment means patients are much less likely to require expensive hospital beds and are more able to continue working and contributing to Europe's economy.
- When it comes to loss of eyesight, more timely diagnosis, intervention and, at the core, research and awareness of the extent of the problem are key.
- Debilitating sight loss can result from such conditions as cataracts (by far the most common reason), diabetic retinopathy, and glaucoma and wet AMD, among other causes.
- There are more cases of cataracts worldwide than there are of the other diseases mentioned above added together. Cataract surgery is very successful, with 90% of patients regaining good vision.
- Diabetes sufferers, meanwhile, are 40% more likely to suffer from glaucoma than those without the disease. The longer a patient has had diabetes, the more common glaucoma is. Age, as ever, also increases risks.
- Patients are frequently excluded from critical aspects of the discussions on preventable blindness/screening and choices surrounding treatment. Their perspectives on ethics and risk-benefit are largely neglected in assessment processes, and they also have little or no say in long-term budget planning or in discussions of pricing and reimbursement of treatments.
- Research into the causes of cataracts and other eye diseases needs boosting across the EU, with platforms for effective collaboration between academia, industry and healthcare systems.