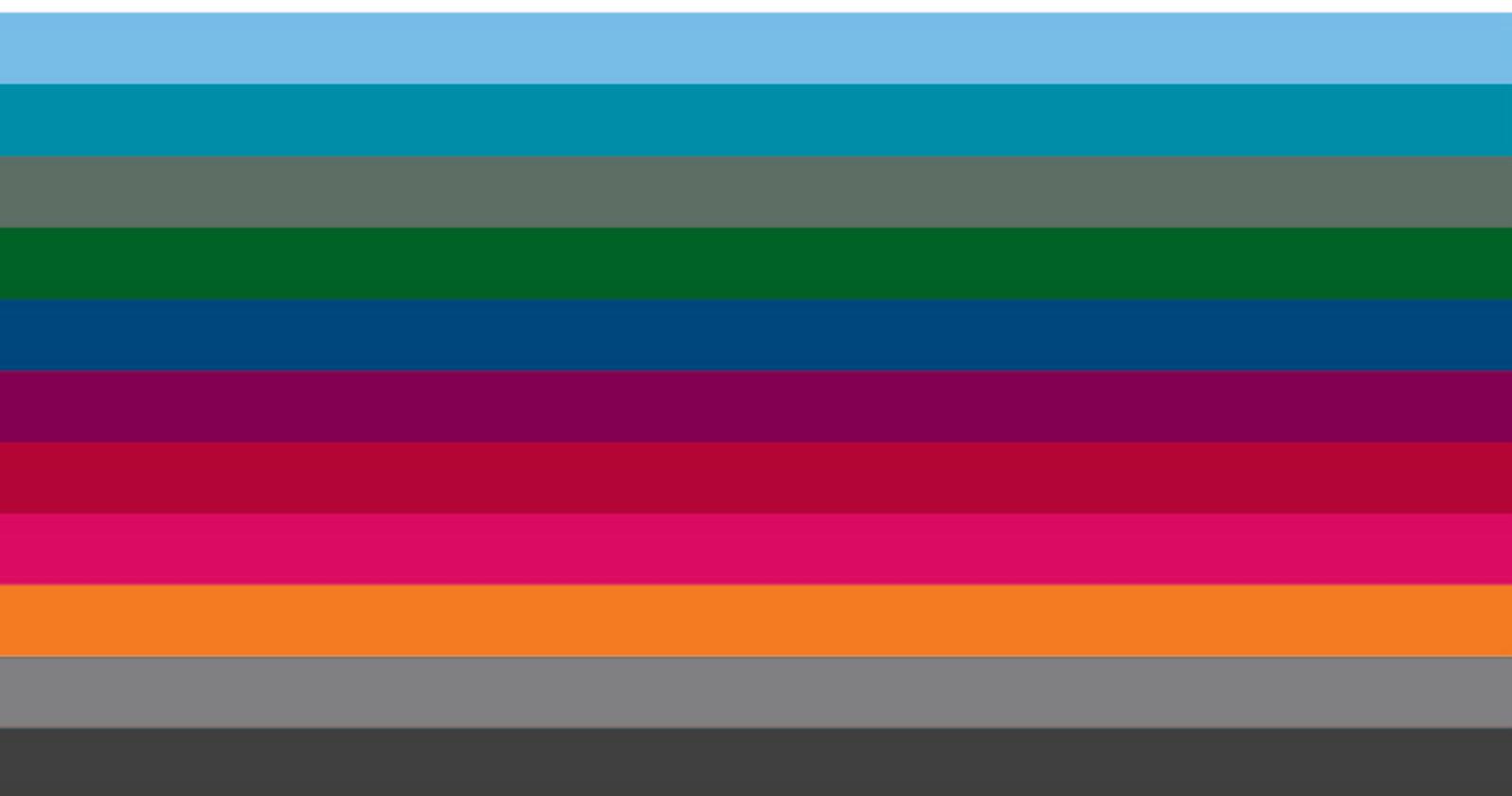


# Framework to Adopt a Strategic Approach for Vision Health in Ireland

**National Coalition for Vision Health in Ireland  
November 2012**



**This report is available in Braille  
and audio upon request from NCBI**

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# Preface

The need to adopt a more strategic approach to the design and development of vision health services in Ireland has been promoted by relevant stakeholders for some time. The Irish Government committed to the objectives of Vision 2020 almost ten years ago. This represents a global collaborative initiative led by the World Health Organisation (WHO) with the overarching objective to eliminate avoidable blindness by 2020. A core requirement to meeting this objective is a national blueprint that identifies collective priorities and outlines a pathway and implementation approach to deliver on these.

The establishment of the HSE National Programme for Eye Care provides real potential to progress quality, access and efficiency objectives with a fundamental objective to reduce the incidence of avoidable sight loss. The development and implementation of fit-for-purpose care pathways and referral protocols offers a real opportunity to transform the service user experience and achieve improved outcomes for people with sight loss in Ireland.

NCBI (Working for people with sight loss) and Fighting Blindness (FB) convened a coalition of varied stakeholders to assist with the development of a framework to adopt a more strategic approach for vision health in Ireland. Following a series of workshops, this National Coalition for Vision Health proposes a number of principles to guide the development of a future national strategy. These include:

- Any future strategy must include the full agenda of eye health for children and adults
- Maximising quality and assuring the safety of all who access services will be the first consideration at all times
- All services and supports will be provided on a person-centred basis with a core emphasis on adopting a life-course approach

- People with sight loss will have the supports in place to enable them to live fulfilled lives, exercising choice and control in their lives
- Services will be provided using seamless pathways traversing health care, social care and the voluntary sector
- Resource allocation and service design will be guided by evidence-based approaches where equality of access to treatment, rehabilitation and support is prioritised
- Research will serve as a key enabler in our continuous commitment to improve outcomes and the quality of care provided
- The strategic development of eye health and support care in Ireland will be aligned as appropriate with the wider Public Health policy framework

Five national objectives are also recommended for inclusion as the basis to structure a comprehensive approach to eliminate avoidable sight loss, improve the overall eye health of the Irish population and ensure that all people who are blind or vision impaired have timely and equitable access to high quality services.

**1**

Improve outcomes achieved and the overall experience of people by ensuring that the necessary linkages between services are in place and that these can be accessed on an equitable and timely basis

**2**

Recognise and resource sight loss prevention and early intervention as a health priority

**3**

Support the general public to achieve a better understanding of good eye health and the primary risks associated with sight loss

Foster the capability of a wider range of health and social care personnel to become referrers to the full spectrum of eye health services

**4**

Position research as a key factor in promoting healthy vision, combating eye disease, eliminating avoidable sight loss and improving quality of care

**5**

The wider impact of blindness on independence and quality of life is acknowledged with user participation and engagement facilitated in the design and delivery of a comprehensive range of support services

The Coalition recognises the strong service delivery record and commitment of a range of different professionals to eye care in Ireland. This is true across primary and secondary care settings. However, as a country we need to adopt a more focussed approach on preventative services and supports. In addition, it is critical that we review how we can better promote and facilitate inclusion, participation and independence for people with sight loss. Success in both of these areas will be dependent on the adoption of a strategic approach that is implemented on a collaborative basis and resourced appropriately.

It is the conclusion of this coalition that a National Vision Strategy should be developed to complement the HSE National Programme for Eye Care. Together, both initiatives will provide the means to:

1. Move towards the elimination of avoidable sight loss,
2. Rebalance the focus on prevention and early intervention, and
3. Provide equitable access to efficient and high quality care, supports and treatment.

This framework was written for an intended audience of policy makers, health planners, relevant service providers and other associated stakeholders. The experience of positioning similar initiatives in Canada, Australia and the UK has been

considered as a means to inform an Irish approach. As joint Chairpersons of this Coalition, we wish to thank and acknowledge the contribution of all Working Group members, those who contributed at the consultation phase, and Novartis Ireland Ltd for the provision of an unrestricted grant to develop this framework.



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**Mr Des Kenny**  
Chief Executive Officer  
NCBI



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**Ms Avril Daly**  
Chief Executive Officer  
Fighting Blindness

# Introduction and Context

This framework has been developed by a coalition of stakeholders with a shared ambition to enhance the approach Ireland takes to prevent avoidable sight loss and promote better eye health amongst children and adults in Ireland [1]. It provides a framework to adopt a strategic approach for vision health in Ireland. The framework aligns with the intent of the HSE National Programme for Eye Care and is entirely supplementary in terms of aims and objectives.

It is recommended that this Framework, and a future National Strategy for Vision Health in Ireland, apply to all service providers working across the public, private and voluntary sectors. In order for such a strategy to be successful it must incorporate all service components for the full agenda of eye health, including prevention, intervention and after care. It should also provide the basis to further promote and facilitate inclusion, participation and independence for people with sight loss.

It is estimated that there are over 220,000 people living in Ireland who are blind or vision impaired [2, 3]. Blindness and vision impairment have a major and wide-ranging impact on peoples' daily lives. This includes a social and economic impact. For example, vision impairment has been shown to double the difficulties associated with daily living activities and halve the ease of social functioning [4].

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1. This document has been developed and approved by a National Coalition for Vision Health in Ireland.  
Please refer to Appendix 2 for breakdown of members.
  2. NCBI (2010) The Cost of Sight Loss – The economic impact of vision impairment and blindness in the Republic of Ireland.
  3. This includes 12,995 people classified as blind. Vision impaired in this instance involves a visual acuity below 6 / 12.
  4. West, S., Munoz, B., Rubin, G. et al (1997) Function and visual impairment in a population-based study of older adults. *Investigate Ophthalmology and Visual Science* 1997;38:72-82.

It is also generally accepted that, despite the best efforts of the healthcare system in Ireland, that a significant proportion of the older population continue to suffer from sight loss which is almost entirely preventable. Some researchers / analysts believe that up to 75% of blindness and vision loss can be avoided [5]. Prevention however requires appropriately resourced early detection and treatment approaches.

The number of people in Ireland with sight loss is projected to increase substantially as the overall population ages. Current Central Statistics Office projections estimate that the number of people aged 65 years and older will almost double over the period 2006 to 2026 [6] (Increasing from approximately 462,000 to 909,000). Increases will be relatively consistent across all of Ireland. Irish and international data shows a marked increase in the frequency of blindness and vision impairment with advancing age. For example, 1 in 5 UK residents aged 75 years and over are living with sight loss. The rate increases to 1 in 2 for people aged 90 and over [7].

There are currently 224,832 people living with low vision and sight loss in Ireland. This is estimated to increase to 271,996 by 2020. Within this, there are approximately 13,000 blind people living in Ireland today, with this expected to increase to 18,000 by 2020 [8]. Given the growing incidence in key underlying causes of sight loss such as obesity and diabetes, this could represent an underestimate if Ireland does not take a comprehensive approach to early detection and treatment strategies.

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5. Australian Institute of Health and Welfare (2005) Vision problems among older Australians
  6. Central Statistics Office (2008) Regional Population Projections 2011 – 2026. Reference: 235 / 2008
  7. <http://www.actionforblindpeople.org.uk/about-us/media-centre/facts-and-figures-about-issues-aroundsight-loss/>  
Accessed on September 18 2012
  8. NCBI (2010) The Cost of Sight Loss – The economic impact of vision impairment and blindness in the Republic of Ireland

Loss of sight has a major personal impact on people’s daily lives. It also has a significant economic impact on individuals, families, society in general and the state. The following tables provide a detailed overview of the costs associated with blindness and sight loss in a given year.

Please note that Real Costs include those relating to the provision of direct healthcare due to blindness / sight loss, lost productivity and informal care costs [9].

<b>Table 1.1 Estimated Cost of Blindness 2010</b>		
<b>Cost of Blindness</b>	<b>Total costs in 2010</b>	<b>Average cost per person in 2010</b>
Real Costs	€ 213,627,305	€ 16,439
Taxation Inefficiency Loss [10]	€ 63,016,816	€ 4,849
Total Direct / Indirect Cost of Blindness	€ 276,644,121	€ 21,289
Disability Adjusted Life Years Lost [11]	5,588	

<b>Table 1.2 Estimated Cost of Sight Loss 2010</b>		
<b>Cost of Blindness</b>	<b>Total costs in 2010</b>	<b>Average cost per person in 2010</b>
Real Costs	€ 281,722,735	€ 1,253
Taxation Inefficiency Loss	€ 104,371,674	€ 464
Total Direct / Indirect Cost of Blindness	€ 386,094,40	€ 1,717
Disability Adjusted Life Years Lost	18,027	

9. Informal care costs is the value of lost working or leisure time for family and friends who assist people with vision impairments with their everyday activities.
10. The Taxation Inefficiency Loss (commonly referred to as the Deadweight Welfare Loss) includes the distorting effects to the economy from raising income tax and other tax revenues to fund government expenditure on eye care, blind welfare payments
11. A Disability Adjusted Life Year (DALY) is used to measure overall disease burden where one DALY represents the loss of the equivalent of one full year of health. A cost is calculated on the basis of this to complete the above analysis.

Please refer to Appendix 1 for more details.

Almost ten years ago the Irish Government made a commitment to Vision 2020. Vision 2020 is a global collaborative initiative led by the WHO with the overarching objective to eliminate avoidable blindness by 2020. An agreed national blueprint, supported by new levels of collaboration, is required to achieve this objective.

The establishment of the HSE National Programme for Eye Care, as led by Mr Paul Moriarty, is a much-welcomed development of the National Coalition for Vision Health in Ireland. Approaches being developed and implemented to progress quality, access and efficiency objectives are extremely timely. In addition, the development and implementation of fit-for-purpose care pathways and referral protocols offer a real opportunity to transform the service user experience and achieve improved outcomes for Irish patients. It is the intention of the National Coalition for Vision Health in Ireland that this submission complements the Programme aims and supports the fast-tracking of implementation timescales where possible.

An extremely diverse range of service providers support the 220,000 people living in Ireland who are blind or vision impaired. The level of integration and coordination between many service providers remains sub-optimal. A National Vision Strategy must outline the components of a fit-for-purpose model of care and the pathway to implement this. It must also place a new focus on preventative services and move service provision to a model that is centred on the needs of individuals.

Research from Australia suggests that up to 75% of blindness and vision loss is preventable or treatable [12]. The healthcare system in Ireland is significantly under performing on the basis of this finding. As the demographic profile in Ireland shifts and increased pressure is placed on available resources, the challenge to provide access to high quality and efficient services will intensify.

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12. Vision 2020 Australia (<http://worldsightday.org.au> - accessed October 8 2012)

Appropriate investment in services supporting the prevention and treatment of people with sight loss is critical. In addition to having a hugely significant impact on the lives of people at risk of sight loss, the return on investment from a state perspective is considerable. It is estimated that appropriate investment can yield a five-fold return [13]. Consideration of how Ireland allocates resources within eye care on a system-wide basis is imperative.

The following section of this document provides a High-level Assessment of the As-Is and in doing so identifies potential areas of focus for a National Vision Strategy.

The potential Role and Objectives of a national strategy are outlined in Section Three.

A high-level Strategic Framework, including potential principles and key national objectives, is recommended by the Coalition in Section Four / Five.

The document concludes with suggested next steps in terms of an approach to complete a comprehensive strategic planning process for eye health in Ireland.

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13. Vision 2020 Australia (2010) The Economic Impact of Vision Loss in Australia in 2009.

## Section 2

# Overview of Key Challenges Associated with Eye Health in Ireland

The core challenges associated with eye health in Ireland are summarised at a high level below according to a number of themes.

### **The Absence of a Collective Voice and Agreed Blueprint**

Eye care in Ireland, including the specialty of ophthalmology, is delivered without an agreed and overarching blueprint to guide service design and provision. In 2003, the Irish Government endorsed VISION 2020 and in doing so agreed to establish a National Coordinating Committee to develop and implement a vision plan.

It could be argued that the absence of a nationally agreed plan has constrained the ability of stakeholders to secure commitment from Government to develop and resource services on a structured and coordinated basis. The absence of such a plan has also meant that a wide-ranging examination of priorities has not taken place.

A number of national plans and strategies are already in existence for specialties and care areas relevant to eye health. The implementation of these will positively impact on the prevention and treatment of eye conditions in Ireland. However, as long as services operate without a specific blueprint for eye health, a consistent and system-wide approach to prevention, treatment and supports in this area will not be possible.

The establishment of a National Programme for Eye Care, as per the HSE National Clinical Programmes, is a most welcome development. The Programme has very specific aims and objectives. This level of specificity represents an entirely positive starting point. It is the assessment of this Coalition that an overarching strategy would significantly benefit future cycles of the National Programme for Eye Care.

## **Insufficient Resources**

Ireland has promoted the development of a community approach to the provision of eye health over many decades with the aim of providing accessible country-wide services close to the service user. This commitment aligns comfortably with the more general healthcare policy of moving care from acute settings to the community. Despite the long-standing commitment to a community approach, community services remain significantly under resourced. A community-based approach offers the potential to significantly enhance access to services through a high quality and cost efficient means. These benefits cannot be achieved however without the allocation of appropriate financial and human resources. A 2010 Manpower Report estimated that an additional 19 Consultant Ophthalmologist and 14 Community Ophthalmologists were required if best practice patient ratios were to be applied. Given retirements during the intervening period it is likely that these deficits have become wider.

Access to specialist services in Ireland is under significant strain for certain procedures and treatments. Access tends to vary by geographic location and by procedure type. At present there are approximately 4,610 patients awaiting cataract surgery. The introduction of intraocular therapies for the treatment of macular degeneration has placed new demands on the healthcare system. Therapies can stabilise loss of vision in 95% of cases and significantly improve it for 30 – 40% of patients. Using UK prevalence data, it is estimated that approximately 22,000 injections per annum are required within Irish public hospitals to meet existing demand [14]. The Irish public healthcare system is insufficiently resourced to treat this volume of patients. The impending roll out of the diabetic retinopathy screening programme in 2013 will significantly support the early detection of sight threatening retinopathy. The introduction of such a programme must be accompanied though with appropriate resources to manage the inevitable upsurge in referrals within the first few years of screening being introduced.

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14. Owen, C.G, Jarrar, Z., Wormald, R et al. (2012) The estimated prevalence and incidence of late stage age related macular degeneration in the UK. *British Journal of Ophthalmology*, [Online First] February 13 2012. [Prevalence data for Ireland is extrapolated on this basis of this study]

Given the economic climate and the likely financial challenges that the healthcare system will face as a result over the coming years, compromises in terms of future service development will be necessary. Budgetary constraints will also continue to have an impact on access to services and medicines. It is imperative however that all services and supports offered within the public healthcare system are provided with patient safety and quality of care at the centre of all decisions. The Health Information & Quality Authority (HIQA) has repeatedly stated that reductions in resource allocation can never be used to justify any compromises in this regard. An overarching strategy would assist with the development of nationally agreed parameters in terms of patient safety and quality of care.

The existing and future potential roles / remits of all professionals associated with eye care, including Eye Doctors, Optometrists, Ophthalmic Nurse Specialists, Dispensing Opticians and Orthoptists, need to be considered in light of the challenges being faced by the healthcare system at present.

### **Suboptimal Levels of Connectivity and Integration**

Facilitating rich levels of communication and connectivity between healthcare professionals is critical to effective and efficient service delivery. Despite the widespread acceptance of this fundamental requirement, maintaining regular interaction between healthcare professionals involved in the provision of eye care remains challenging. These challenges are intensified due to the fact that the majority of service users are older and typically have co-morbid conditions. As a result, communication between professionals and clarity in terms of role and remit are essential for efficient and high quality service delivery.

The experience from other jurisdictions where IT infrastructure enables communication across traditional boundaries is that improvements are offered in terms of (1) continuity of care, (2) access to specialists, (3) overall convenience and (4) general information transfer. Consequently the experience of people with sight loss is enhanced and service delivery is achieved on a more efficient basis.

The development of standardised pathways and referral protocols (as included within the remit of the National Programme for Eye Care) for the treatment of AMD, Diabetic Retinopathy, Cataract, Glaucoma and Paediatric Ophthalmology is a timely development in the view of all coalition members. These pathways and protocols must be supported by appropriate information technology linking hospital and community services however.

The combination of (1) agreed pathways / referrals processes and (2) IT infrastructure to join service providers offers a real opportunity to transform service delivery in Ireland. Without both components supporting each other, Ireland will continue to offer a fragmented service and will limit opportunities to leverage available service-related efficiencies.

Service delivery in Ireland involves a range of different stakeholders and service providers, from voluntary organisations to tertiary care service providers. As a result, appropriate levels of connectivity between these stakeholders are fundamental to the provision of high quality and efficient service delivery. The healthcare system must facilitate and enable connectivity where required with the integration and coordination of supports / services being a fundamental objective of any future strategy.

### **Gaps in the Continuum of Care**

Service delivery models must also be designed and implemented with a full spectrum of service components included. Any future service delivery model must facilitate seamless and effortless movement of people with sight loss between supports. For example, social, psychological and emotional support requirements are likely to vary as a person comes to terms with blindness or experiences vision impairment. It is imperative that services are designed with the necessary flexibility and linkages to assist all service users.

As stated previously in the document, a marked increase in the frequency of blindness and vision impairment is associated with advancing age. This has significantly important implications for the design and delivery of services for older persons, who will typically be compromised to some degree

by infirmity and may also have co-morbid conditions. As the population in Ireland ages this will pose greater challenges on the healthcare system.

In addition, vision loss prevents health and independent ageing and is associated with the following [15]:

- Risk of falls increases by a factor of 2
- Risk of depression increases by a factor of 3
- Risk of hip fractures increases four to eight times
- Admission to nursing homes takes place up to three years earlier
- Twice as likely to use health services

Given the above, it is imperative that interdependencies between services are understood and that a system-wide focus is taken to ensure services are integrated where this promotes a person-centred approach.

Such a system-wide focus must also include initiatives to promote and foster the inclusion, participation and independence of people with sight loss. For example, everyday activities including those associated with education, employment, and leisure should be accessible to vision-impaired people of all ages.

### **Balancing Commitments Between Prevention and Cure / Care**

As with all areas of service provision in the healthcare landscape, ensuring that resources are used efficiently is critical. A review of resource allocation across community and acute services is required with a specific emphasis on achieving an appropriate balance between prevention and treatment.

The introduction of a Diabetic Retinopathy Screening Programme is an extremely positive development [16]. It should be noted however that a similar programme was first rolled out in England almost ten years ago. While screening

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15. Vision 2020 Australia (2010) The Economic Impact of Vision Loss in Australia in 2009.

will greatly improve detection rates of treatable disease there will be an initial increased demand on services that are already extremely stretched from a capacity perspective. Future investment decisions in relation to screening programmes and early treatment should be informed by a national strategy outlining an agreed pathway for a more prevention-focussed national model of care.

### **Knowledge, Information and Research Deficits**

Ireland is not unique in the sense that knowledge deficits exist within the general public regarding eye health and the risks of avoidable blindness. A range of associated organisations has introduced various activities and initiatives to promote awareness and understanding of these issues. Applying a coherent and well structured national approach to promotional activities would assist in achieving maximum impact with key target audiences.

A number of Clinical Research Centres are in place across Ireland and focus on a diverse range of research objectives. Despite this, Ireland continues to underperform in terms of the completion of clinical trials. There are a number of reasons for this (e.g. absence of robust Irish datasets, lack of protected time for the completion of research within clinical settings, etc), none of which should be insurmountable. In attracting more research to Ireland, a more long term and strategic outlook is necessary.

The lack of robust datasets and commitment to the development of Information Communication technology (ICT) infrastructure, not only limits the attractiveness of Ireland as a site for clinical trials, but also significantly curtails the ability of service planners to link existing and emerging demand with resources. Ireland is reliant on international data when developing forecasts regarding future demand, and consequently the quantification of future required resources.

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16. In 2010 the Health Service Executive announced funding for the Diabetic Retinopathy Screening Programme. The Programme is currently being developed by the National Cancer Screening Service (NCCS) and will be aimed at persons with diabetes aged 12 years and over. It is estimated that this involves an approximate population of over 170,000. The NCCS continues to progress this development.

### Section 3

# The Role of a Future National Strategy

It is envisaged that the development process and, more importantly, the completion of an agreed National Vision Health Strategy will provide numerous direct and indirect benefits. First and foremost the strategy should provide the basis to transform the experience of people with sight loss and ensure that, regardless of location in Ireland, that all have timely access to high quality, safe and efficient services. It should also serve to significantly improve the capability of Ireland to prevent avoidable sight loss.

#### **The strategy development process will require that:**

- Key national priorities for eye care are widely discussed and considered
- All challenges and limitations associated with the as-is are reviewed and that options to alleviate and remove these are evaluated on a transparent and consistent basis
- Stakeholders are engaged and consulted with throughout the process to ensure that all views / suggestions are taken on board
- International best practice is considered as appropriate
- Available evidence based research is reviewed and considered
- Current resource allocation across community and acute services is reviewed

### **The finalised strategy will:**

- Provide a blueprint for the development and provision of eye health services in Ireland
- Take a longer term view in terms of the evolving needs and preferences of service users
- Build on the threefold focus (quality, access, cost) of the National Programme for Eye Care
- Ensure that a more balanced approach is taken to the provision of services focused on prevention, early intervention and treatment
- Identify opportunities to optimise the role and remit of various health and social care professionals (including Optometrists, Ophthalmic Nurse Specialists, Opticians and Orthoptists) capable of supporting eye health service provision for the ultimate benefit of people with sight loss in Ireland
- Facilitate enhanced levels of integration and connectivity between health and social care professionals (both those working directly in eye health and those supporting other related service areas – for example, Services for Children and Young People, Services for Older Persons, Disability Services)
- Focus on supporting the shift from acute care to community care where appropriate

- Ensure that the full spectrum of service delivery is incorporated into one comprehensive model of care
- Identify and prioritise the role of key enablers such as investment in required ICT infrastructure
- Outline a phased implementation approach that is based on realistic starting points and takes into account the economic realities of present day Ireland
- Optimise the use of available resources and deliver efficiencies within the medium term
- Consolidate a partnership approach and a new culture of cooperation amongst all key health and social care professionals supporting the provision of high quality eye health services in Ireland

The successful implementation of a national strategy will ensure that the Irish public are better informed as regards the risks of sight loss and eye disease in general. This increased awareness should translate into improved levels of individual responsibility, which is a critical requirement for early intervention and preventative approaches to function as intended.

## Section 4

# Principles for a National Strategy

The Coalition suggests that a National Vision Strategy should be developed on the basis of the following eight principles. This mix of principles represents the core beliefs shared by members of this Coalition regarding the future design and deliver of services / supports relevant to eye health.

**1**

Any future strategy must include the full agenda of eye health for children and adults

**2**

Maximising quality and assuring the safety of all who access services will be the first consideration at all times

**3**

All services and supports will be provided on a person-centred basis with a core emphasis on adopting a life-course approach

**4**

People with sight loss will have the supports in place to enable them to live fulfilled lives, exercising choice and control in their lives

**5**

Services will be provided using seamless pathways traversing health care, social care and the voluntary sector

**6**

Resource allocation and service design will be guided by evidence-based approaches where equality of access to treatment, rehabilitation and support is prioritised

**7**

Research will serve as a key enabler in our continuous commitment to improve outcomes and the quality of care provided

**8**

The strategic development of eye health and support care in Ireland will be aligned as appropriate with the wider Public Health policy framework

All future service reconfiguration programmes and implementation plans associated with a National Vision Strategy should apply these overarching principles to test their overall alignment with the strategy and to evaluate if future plans have the necessary breadth and depth.

## Section 5

# Key National Objectives for Consideration

It is proposed that the National Vision Strategy be designed and implemented around five national objectives as follows:

**1**

### **Co-ordination and Integration of Services**

Improve outcomes achieved and the overall experience of people by ensuring that the necessary linkages between services are in place and that these can be accessed on an equitable and timely basis

**2**

### **A Core Focus on Prevention and Early Intervention**

Recognise and resource sight loss prevention and early intervention as a health priority

**3**

### **Knowledge and Awareness**

Support the general public to achieve a better understanding of good eye health and the primary risks associated with sight loss

Foster the capability of a wider range of health and social care personnel to become referrers to the full spectrum of eye health services

**4**

### **Research**

Position research as a key factor in promoting healthy vision, combating eye disease, eliminating avoidable sight loss and improving quality of care

# 5

## **Inclusion**

The wider impact of blindness on independence and quality of life is acknowledged with user participation and engagement facilitated in the design and delivery of a comprehensive range of support services

# 1 Co-ordination and Integration of Services

Improve outcomes achieved and the overall experience of people by ensuring that the necessary linkages between services are in place and that these can be accessed on an equitable and timely basis

## Additional Detail

It is envisaged that this objective will build on the aims and work to date of the National Programme for Eye Care with a core focus on enhancing equitable access to high quality services. For example, the objective would likely focus on:

- Ensuring that the model of care for associated services incorporates all required service components from highly specialised surgical procedures in an acute setting to the provision of rehabilitation and emotional support in community settings convenient for people with sight loss
- Promoting an equitable balance of commitments in terms of the development of all service components including emotional support, counselling, support networks, rehabilitation, compensatory training, access to technical and low vision aids
- Promoting an appropriate balance of roles and responsibilities across health care professionals, including Eye Doctors, Optometrists, Ophthalmic Nurse Specialists, Dispensing Opticians and Orthoptists, as a means to enhance access to services / supports
- Enhancing levels of connectivity between related service providers using ICT infrastructure and team-based approaches where appropriate
- Achieving improved degrees of integration across traditional boundaries (e.g. hospital and community, health and social care)

- Establishing stronger links between related service areas (e.g. services for children and young people with sight loss and / or complex needs, services for older persons, disability services, primary care, mental health) as a means to ensure that the multiple and varied needs of service users are responded to
- Adopting a lifecourse approach to service design and delivery to facilitate seamless transitions from services for children, to young people, to adults and older persons

The achievement of enhanced access to high quality services will ultimately have a significantly positive impact on efficiency of service delivery and overall value for money. A comprehensive and fit-for-purpose model of care will ensure that service users receive the support / care they require at the right place and at the right time.

## 2 A Core Focus on Prevention and Early Intervention

Recognise and resource sight loss prevention and early intervention as a health priority

### **Additional Detail**

A key requirement to prevent avoidable sight loss is an appropriate focus on prevention and early intervention. On this basis, it is recommended that this objective include consideration of the following:

- The introduction of targeted prevention campaigns for key at-risk groups
- Building capacity amongst the primary and community care workforce to identify early symptoms and refer onwards appropriately
- The provision of timely and equitable access to a full myriad of early intervention approaches including sight tests, screening programmes
- Ensuring that all future service delivery networks are equipped and resourced appropriately to deliver on prevention targets
- The expansion of screening programmes with a particular emphasis on high risk groups
- The provision of supports to assist health care professionals with the early identification of conditions / disease
- Equitable and consistent accessibility to required services, treatments and supports
- The continuous promotion of awareness amongst those of increased risk (e.g. older persons, people with diabetes) and their health care providers of the need for regular eye examinations
- Introduction of initiatives to ensure teachers and other professionals working with children are aware of visual difficulties, the effect on learning and where / how to refer onwards

Given (a) the high percentage of avoidable sight loss cases and (b) the significant direct and indirect costs associated with sight loss, it is imperative that our focus as a nation on prevention and early intervention is intensified and resourced appropriately.

### 3 Knowledge and Awareness

Support the general public to achieve a better understanding of good eye health and the primary risks associated with sight loss

Foster the capability of a wider range of health and social care personnel to become referrers to the full spectrum of eye health services

#### **Additional Detail**

A critical component of successful early detection initiatives involves educating the general public about detection, the importance of recognising symptoms and discussing these with suitably qualified and experienced healthcare professionals. This twofold national objective should involve the following key components:

- The design and implementation of public health and education campaigns to raise awareness about the risk factors for eye disease and injury, the importance of healthy lifestyle behaviours to prevent eye disease, and the prevention of chronic diseases that can have implications for vision
- Production of targeted eye health communication materials for specific audiences (e.g. health and social care personnel, parents, teachers, older people)
- Increasing awareness of relevant intervention and outreach services among individuals with sight loss and their families
- Building the capacity of general practitioners, pharmacists, allied health professionals and other relevant health care personnel to provide advice and information to the public regarding the maintenance of good eye health
- Enhancements to the training and development programmes of health and social care professionals in order to develop effective referral agents across the system
- Enhancements to the Continuing Professional Development programmes of health and social care professionals in order to extend the knowledge and expertise of potential referral agents across the system

Greater knowledge and awareness amongst the general public will result in an improved and earlier uptake of services and supports. Greater awareness amongst healthcare professionals will promote increased levels of confidence and competence to refer service users. Both of these characteristics are necessary if Ireland is to reduce the incidence of avoidable blindness.

## 4 Research

Position research as a key factor in promoting healthy vision, combating eye disease, eliminating avoidable sight loss and improving quality of care

### **Additional Detail**

Research offers an essential enabler to improve outcomes and the quality of life of service users. Despite significant progress in recent years, Ireland continues to lack some of the basic requirements for the completion of comprehensive research programmes in the area of eye health. This objective should concentrate primarily on the following:

- The introduction of appropriate IT to enable the collation and analysis of robust Irish patient / service user registries
- Identification of key eye health research gaps from an Irish context and the prioritisation of areas of focus in the short, medium and longer term
- Securing and overseeing the completion of clinical trials
- Developing a more focused and consistent approach on clinical audit
- Supporting the development of an evidence base for population health approaches to reduce the risk of blindness and vision loss
- Promoting a strong evaluation culture amongst all professionals associated with eye health
- The introduction of effective knowledge transfer strategies to disseminate key research findings to professionals delivering eye health services

While it is recognised that databases and paper records of people affected by vision impairments exist in many centres around Ireland, the development of a centralised register of eye conditions is extremely overdue. Such a register would serve as a significant resource for research

and service planning purposes. Centralised registers have been successfully introduced in neighbouring countries and have had an immediate impact in terms of the quality of care delivered and the achievement of service delivery efficiencies.

Eye health research should be wide-ranging and should extend over all key areas including clinical research, translational research, prevention research and epidemiological research. It is expected, provided it is successfully delivered on, that this objective will have a significant contribution to make to all pillars of a future national strategy.

The Vision Impaired Service Providers Alliance (VISPA) estimates that less than 2% of our total research spend is in vision research [17]. After factoring in the additional contribution from charity fundraising, this does not provide an appropriate foundation for the completion of the level and breadth of research programmes that Ireland should be committed to.

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17. <http://www.vispa.ie/index2.html> - accessed October 3 2012

## 5 Inclusion

The wider impact of blindness on independence and quality of life is acknowledged with user participation and engagement facilitated in the design and delivery of a comprehensive range of support services

### **Additional Detail**

A Vision Health strategy must acknowledge the wider impact of blindness on independence and quality of life. In doing so, it must acknowledge the need for statutory support for the development and maintenance of a comprehensive range of compensatory support services. This should range from emotional support, counselling and psychological supports, to rehabilitation and public awareness programmes.

A core target of the strategy should be to support people with sight loss to make informed decisions relating to their treatment, care and support. The views and experiences of all should serve as a fundamental component to the design and delivery of future services. In addition, the strategy should place a core emphasis on promoting inclusion, participation and independence for children and adults with sight loss.

It is envisaged that this objective will place a core focus on the following:

- Improving and facilitating the transition from medical to social supports
- The provision of rapid access to services / supports for children and adults at the point of diagnosis
- Ensuring that a comprehensive range of support services are available on an equitable and consistent basis
- The provision of first-rate low vision services
- The introduction and consistent implementation of a comprehensive needs assessment process, covering all aspects of life (including daily living, mobility, low vision aids, communication equipment, housing adaptations and individual budgets)

- Ensuring that benefit / allowance schedules and scales offer graduated payments which acknowledge the additional financial costs arising from sight loss
- Ensuring that a range of channels exist to capture the voice of service users, that inputs are responded to, and that required service developments and improvements are acted on as appropriate
- The introduction of new approaches to facilitate appropriate involvement of patients and service users in their own care
- Improved levels of coordination between partnerships and stakeholders at national and international level in the field of research
- Strategies to ensure equitable access to education, training, employment and leisure activities

Key policy and service development initiatives relevant to eye health should offer a meaningful role for user groups and sight loss agencies.

Stronger partnerships between policy makers, service providers and service users are a core requirement to make everyday activities (transport, leisure, employment, education) more accessible to people of all ages with sight loss.

# Conclusion and Next Steps

This document makes a further call for the development of a National Vision Strategy. Recognising the formal commitment of the Irish Government to VISION 2020 in 2003, it provides the basis to develop a detailed national blueprint. It also demonstrates the commitment between diverse, but related, stakeholders to progress joint objectives for the ultimate benefit of people living in Ireland who are blind or have a vision impairment.

The Irish Government has invested and continues to invest resources in the provision of eye health. The Coalition recognises the strong service delivery record and commitment of a range of different professionals to eye care in Ireland. This is true across primary and secondary care settings. Ensuring that future investment is strategic and coordinated in line with agreed national objectives is critical however if Ireland is to meet the evolving needs of people who are blind or vision impaired.

Current approaches to service delivery will be reformed as part of the National Programme for Eye Care. All members of this Coalition welcome such refinements and look forward to contributing to the implementation of the Programme when finalised.

Adopting a more strategic and integrated approach to vision health offers the opportunity to have a significantly positive impact on the lives of the 224,832 people living with low vision and sight loss in Ireland today. For example, a recent Danish study found that the incidence of legal blindness attributable to age-related macular degeneration (AMD) decreased by approximately 50% between 2000 and 2010 [18]. The incidence of legal blindness from causes other than AMD decreased by 33% during the same period. This study offers further encouragement that where healthcare systems adopt a more focussed approach to the full spectrum of vision health services / supports, from early diagnosis in primary

care settings to specialist treatment in acute settings, then outcomes for people at risk of sight loss can be significantly improved.

It is the conclusion of the Coalition that it is necessary that an overarching National Vision Strategy now complement the HSE National Programme for Eye Care. Together, both initiatives will provide the means to:

1. Move towards the elimination of avoidable sight loss,
2. Rebalance the focus on prevention and early intervention, and
3. Provide equitable access to efficient and high quality care, supports and treatment.

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18. Bloch, S.B., Larsen, M., Munch, I.C. (2012) Incidence of Legal Blindness From Age-Related Macular Degeneration in Denmark: Year 2000 to 2010. *American Journal of Ophthalmology* Vol. 153, No. 2: 209-213

# Cost of Sight Loss [19]

## 1. Health Care System Costs

The direct cost of vision impairment and blindness to the Irish health care system was estimated at €116.75m in 2010. This represents that as paid by government and individuals.

It includes both public and private hospital costs. The total figure is broken down as follows:

- Hospital Costs - €70.06m (60%)
- Prescription Drug Costs - €16.58m (14%)
- General Ophthalmic Services - €15.76m (14%)
- Other Costs - €14.36m (12%)

Other costs refer to those including eye examinations for people who are vision impaired, appliances (e.g. spectacles), and other assessment and care funded by the public health care system.

The indirect cost of vision impairment and blindness is estimated to add €269.34m to the overall cost. This represents 70% of the total estimated cost and includes three key components:

- Informal Care Costs - €108.25m (40%)
- Deadweight Welfare Loss - €104.37m (39%)
- Productivity Losses - €56.72m (21%)

The sum of direct and indirect costs is €386.08 million. This is the estimated total financial cost of vision impairment and blindness in the ROI in 2010. In order to calculate the economic cost of vision impairment and blindness, the cost of disease burden must be added to the financial cost. Therefore the total economic cost of vision impairment and blindness in the ROI in 2020 is estimated to have been €2,143,252,300 in 2010.

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19. NCBI (2010) The Cost of Sight Loss – The economic impact of vision impairment and blindness in the Republic of Ireland

## 2. Vision Loss in the Future

The authors of the report estimate that the number of people with vision impairment or blindness will increase by 21% between 2010 and 2020. It is estimated that there will be 271,996 people living in Ireland with vision impairment or blindness by 2020.

## 3. Future Cost Projections

The Burden of Vision Impairment and Blindness in Ireland

<b>Cost Component</b>	<b>2010</b>	<b>2015</b>	<b>2020</b>
<b>Direct Health Care Costs (a)</b>	€116.8 m	€127.4 m	€136.8 m
<b>Indirect Costs (b)</b>	€269.3 m	€292.3 m	€312.2 m
- Productivity Losses	€56.7 m	€60.6 m	€63.7 m
- Informal Care	€108.2 m	€118.1 m	€126.8 m
- Deadweight Welfare Loss	€104.4 m	€113.6 m	€121.6 m
<b>Total Financial Cost (a)+(b)</b>	€386.1 m	€419.7 m	€449 m
<b>Burden of Disease (c)</b>	€1,757.2 m	€1,972.1 m	€2,224.4 m
- Total DALYs	18,537	20,804	23,465
<b>Total Economic Cost (a) + (b) + (c)</b>	€2,143.3 m	€2,391.9 m	€2,673.4 m

# Cost of Blindness [20]

The methods used in the study referenced in Appendix 1 did not differentiate the cost of sight loss by degree of vision impairment. Therefore further research has been undertaken to identify the cost of blindness (vision acuity of <6 / 60 in an individual's better seeing eye). This research suggests that blindness accounts for 72% of the total financial cost of sight loss in the ROI, while mild and moderate vision impairment account for 28% of the total cost of sight loss. A breakdown of the costs of blindness is outlined below:

<b>Cost Component</b>	<b>2010</b>	<b>2015</b>	<b>2020</b>
<b>Direct Health Care Costs (a)</b>	€4.3 m	€4.8 m	€5.3 m
<b>Indirect Costs (b)</b>	€272.3 m	€315 m	€361.6 m
- Productivity Losses	€57.9 m	€63 m	€67.8 m
- Informal Care	€151.4 m	€177.9 m	€209.7 m
- Deadweight Welfare Loss	€63 m	€74 m	€84.2 m
<b>Total Financial Cost (a)+(b)</b>	€276.6 m	€319.8 m	€367 m
<b>Burden of Disease (c)</b>	€532.6 m	€626 m	€738.4 m
- Total DALYs	5618	6604	7789
<b>Total Economic Cost (a) + (b) + (c)</b>	€809.2 m	€945.8 m	€1,105.3 m

20. NCBI (2012) The Cost of Blindness in the Republic of Ireland – Please note that this is a provisional title for an upcoming study being launched in November 2012.

## Appendix 3

# Working Group

The following individuals were members of the Working Group that oversaw the development of this submission:

<b>Name</b>	<b>Organisation</b>	<b>Role / Profession</b>
1 Ms Avril Daly (Co-chair)	Fighting Blindness	CEO
2 Mr Des Kenny (Co-chair)	NCBI	CEO
3 Mr Mark Cahill	RVEEH	Consultant Ophthalmic Surgeon
4 Ms Anne Marie Costello	ChildVision	Family Resource Coordinator
5 Dr Maureen Hillery	HSE	Community Ophthalmic Physician
6 Mr David Keegan	MMUH	Consultant Ophthalmic Surgeon
7 Ms Siobhan Kelly	Irish College of Ophthalmologists	CEO
8 Mr Gerry Kerr	Service User Representative	Service User Representative
9 Ms Patricia Logan	Irish College of Ophthalmologists	President
10 Ms Lynda McGivney Nolan	Association of Optometrists	Professional and Optometric Advisor
11 Mr David McMahon	Diabetes Federation of Ireland	Advocacy Communication Manager
12 Mr Pdraig Mallon	Irish Guide Dogs for the Blind	CEO
13 Ms Deirdre Moriarty	Irish Guide Dogs for the Blind	Client Services Manager
14 Ms Irene Reid	National Rehabilitation Hospital	Senior Orthoptist



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