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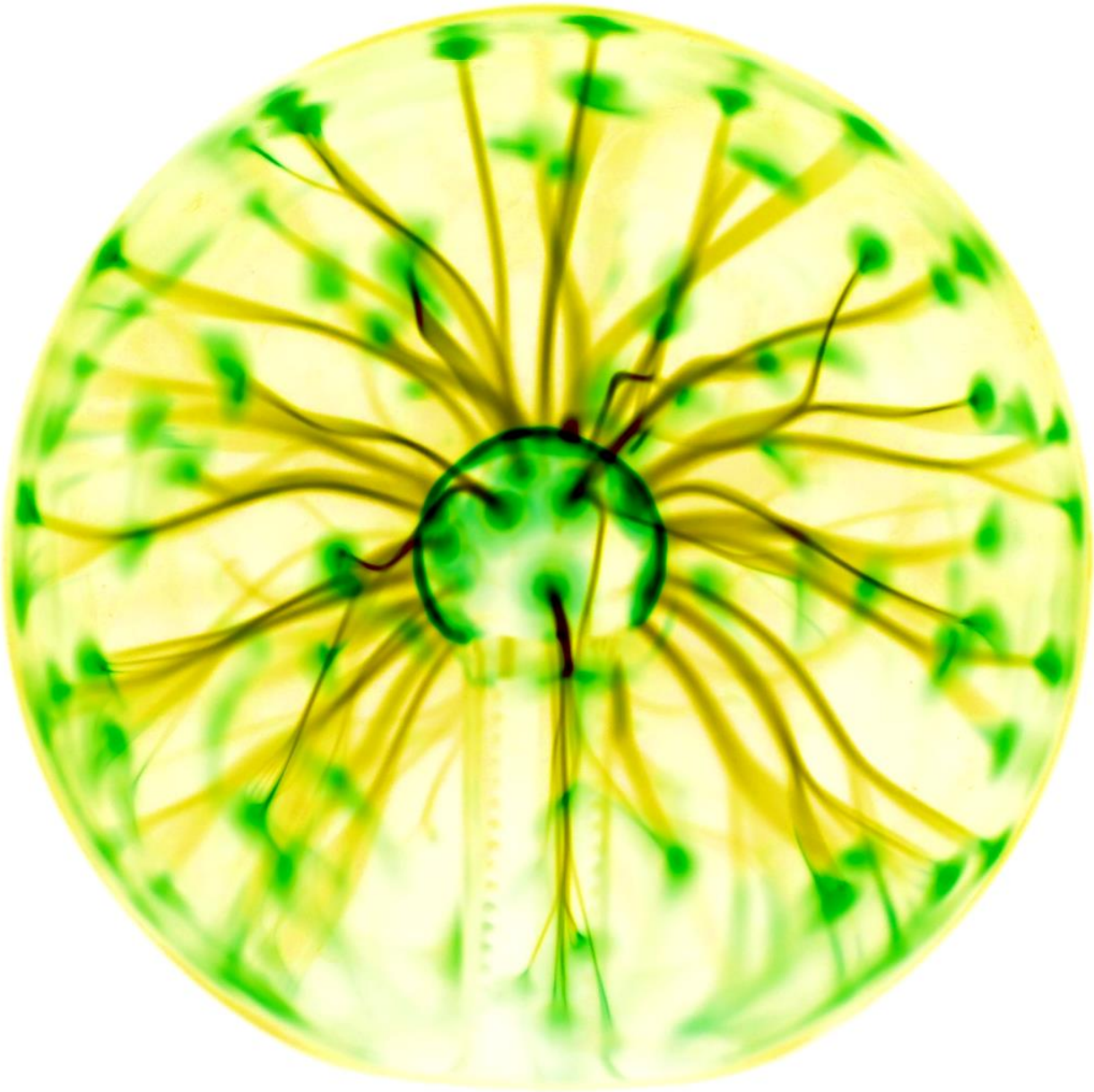

The socioeconomic impact of inherited retinal dystrophies (IRDs) in the Republic of Ireland

Retina International

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Deloitte
Access Economics

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Glossary

Acronym	Full name
AMD	age-related macular degeneration
AWE	average weekly earnings
CBA	cost benefit analysis
CEA	cost effectiveness analysis
CMA	cost minimisation analysis
CPI	consumer price index
CSO	Central Statistics Office Ireland
CUA	cost utility analysis
DALY	disability adjusted life year
DCA	Domiciliary Care Allowance
DES	Department of Education and Skills
DLTV	Daily Living Tasks Dependent on Vision Questionnaire
DPER	Department of Public Expenditure and Reform
DVA	distance visual acuity
DWL	deadweight loss
EOSRD	early onset severe retinal dystrophy
ERG	electroretinography
FTS	free travel scheme
GDPR	European Union General Data Protection Regulations
GP	general practitioner
GPS	Global Positioning System
HID	handicaps, incapacités, dépendance
HM	Her Majesty's
HRB	Health Review Board

Acronym	Full name
HSE	Health Service Executive
IACP	Irish Association for Counselling and Psychotherapy
ICER	Institute for Clinical and Economic Review
IMHE	Institute for Health Metrics and Evaluation
IRD	inherited retinal dystrophy
LAI	Living Alone Increase
LCA	Leber congenital amaurosis
LFS	labour force survey
NCSE	National Council for Special Education
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OECD	Organization for Economic Cooperation and Development
ONS	Office for National Statistics
PPP	purchasing power parity
RoI	Republic of Ireland
RP	retinitis pigmentosa
RPE	retinal pigment epithelium
SEN	special education needs
SNA	special needs assistance
SPPF	shadow price of public funds
SSI	severe sight impairment
UK	United Kingdom
US	United States of America
USH1	Type 1 Usher syndrome
VI	visual impairment

Acronym	Full name
VSLY	value of a statistical life year
VTS	Visiting Teacher Service
wAMD	wet age-related macular degeneration
WHO	World Health Organization
XLRS	X-linked retinoschisis
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

Foreword

This work was funded and supported by IRD COUNTS who recognised the need to better understand the real impact of inherited retinal dystrophies (IRDs) in the Republic of Ireland (RoI) and, the United Kingdom (UK) of Great Britain and Northern Ireland.

IRD COUNTS is a consortium of patient-led organisations, industry and clinician partners who assisted in the design of the project and recruitment of survey participants.

IRD COUNTS partners: Fighting Blindness Ireland, Retina UK, Thomas Pocklington Trust, F.Hoffmann-La Roche, MeiraGTx, Novartis Limited UK, ProQR.

IRD COUNTS is managed by Retina International.

The socioeconomic impact of inherited retinal dystrophies (IRDs) in the Republic of Ireland (RoI)

Executive summary

Methodology

The socioeconomic burden of inherited retinal dystrophies (IRDs) in the Republic of Ireland (RoI) was estimated using cost-of-illness methodology applying a prevalence approach (Larg & Moss, 2011). This approach involves estimating the number of people with IRDs in a base period (2019) and the costs attributable to IRDs in that period. The analysis was based on a targeted literature review and primary data (survey) collection.

Prevalence

Overall, the prevalence of IRDs in the RoI was estimated at 0.03% or 1,522 prevalent cases in 2019.

The highest proportion of the overall prevalence was attributed to retinitis pigmentosa (RP) (49.6%, 755 people), followed by Usher syndrome (12.4%, 189 people).

Table 1: Prevalence of IRDs in the RoI (n, 2019)

IRD	Cases
RP	755
Usher syndrome	189
Stargardt disease	154
LCA/EOSRD	116
Best disease	73
Cone dystrophy	64
Cone-rod dystrophy	59
Achromatopsia	54
XLRS	35
Choroideremia	22
Total	**1,522**

Total costs

Total costs attributable to IRDs in the RoI were estimated to be €49.5 million in 2019, comprising both economic (€33.5 million) and wellbeing costs (€16.0 million).

Of the ten IRDs within scope, RP incurred the greatest proportion of total costs at €24.9 million (50.3%), followed by Usher syndrome (€6.2 million, 12.5%), Stargardt disease (€4.9 million, 9.9%), LCA/EOSRD (€3.6 million, 7.2%), Best disease (€2.3 million, 4.7%), cone dystrophy (€2.1 million, 4.2%), cone-rod dystrophy (€1.9 million, 3.9%), achromatopsia (€1.7 million, 3.4%), XLRS (€1.2 million, 2.4%) and choroideremia (€0.7 million, 1.4%). Wellbeing costs comprised the largest share of total costs at €16.0 million (32.3%), followed by productivity costs (€9.4 million, 18.9%), deadweight losses (€8.2 million, 16.6%) other costs (€7.0 million, 14.2%) and informal carer costs (€6.7 million, 13.6%).

Chart 1: Total costs of IRDs (€ million, 2019) in the RoI by condition

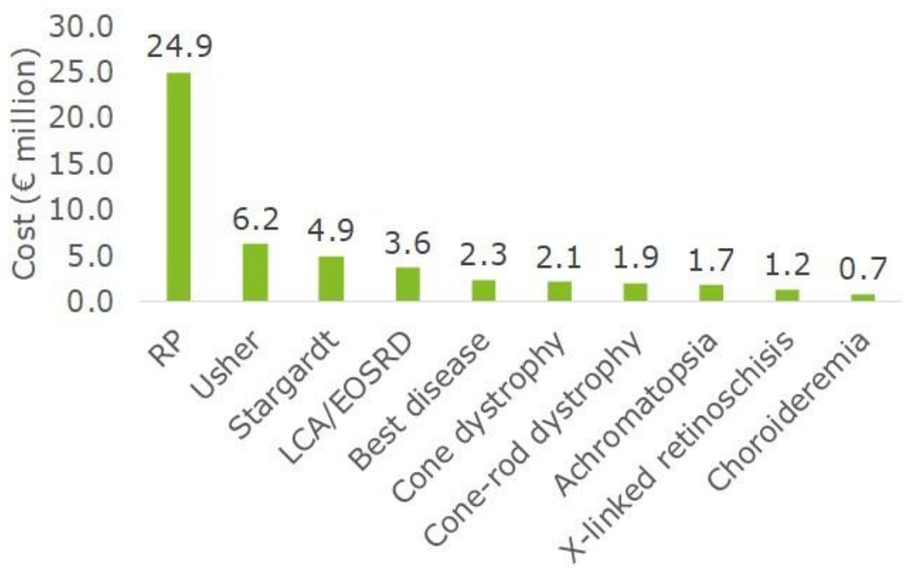


Table 2: Total costs of IRDs (€ million, 2019) in the RoI by cost type

Cost type	Percentage (%) of total costs	Cost (€ million)
Wellbeing costs	32.3	16.0
Productivity costs	18.9	9.4
Deadweight losses	16.6	8.2
Other costs	14.2	7.0
Informal carer costs	13.6	6.7
Health system costs	4.5	2.2
Total cost	**100**	**49.5**

Conclusion

IRDs imposed significant economic and wellbeing costs on the RoI population in 2019. Persons living with an IRD incur significant economic costs and reductions in their quality of life. Significant economic costs are also borne by families, friends, government, employers and society.

1 Introduction

The socioeconomic burden of inherited retinal dystrophies (IRDs) in the Republic of Ireland (RoI) was estimated using best practice cost-of-illness methodology applying a prevalence approach. The analysis was based on data collected in a targeted literature review and primary (survey) data collection.

1.1 Purpose

Retina International on behalf of the IRD COUNTS consortium engaged Deloitte Access Economics to estimate the disease burden and economic impact of IRDs in the RoI and the UK from a societal perspective – a cost-of-illness study. This approach involves estimating the number of people with IRDs in a base period (2019) and the costs attributable to IRDs in that period.

Cost-of-illness studies are conducted with the intent of describing the economic burden imposed by a disease, on a specific population (Larg & Moss, 2011). The proprietary Deloitte Access Economics cost-of-illness methodology estimates both economic and wellbeing costs.

The results from a cost-of-illness study can be used to define the economic burden of a disease, justify investment in preventive or treatment interventions, inform funding allocation and prioritisation, provide a basis for policy and planning, and provide inputs for economic analyses (Rice, 2000; The Joanna Briggs Institute, 2014).

1.2 This report

This report outlines the disease burden and economic impact of IRDs in the RoI in 2019.

To facilitate accessibility, non-standard formatting has been used throughout this report. This includes size 14 font and darker headings. In addition, spacing within the tables has been increased and pages containing detailed charts and tables have been converted to landscape.

The remaining sections of this report are set out as follows:

- Chapter 2: Background
- Chapter 3: Methodology
- Chapter 4: Survey results
- Chapter 5: Prevalence
- Chapter 6: Health system costs
- Chapter 7: Individual productivity costs
- Chapter 8: Other costs
- Chapter 9: Wellbeing costs
- Chapter 10: Sensitivity analysis
- Chapter 11: Conclusion
- References
- Appendices.

2 Background

IRDs represent a diverse group of progressive, visually debilitating diseases for which there have traditionally been no effective treatments to restore vision.

IRDs are genetically diverse with over 260 genes currently linked to this group of diseases (Duncan et al, 2018).

This report focuses on the following ten IRDs, a list determined by Retina International and the IRD COUNTS consortium:

- Retinitis pigmentosa (RP)
- Leber congenital amaurosis (LCA)/early onset severe retinal dystrophy (EOSRD)
- Cone dystrophy
- Choroideremia
- Usher syndrome
- Best (vitelliform) macular dystrophy (Best disease)
- Code-rod dystrophy
- Stargardt disease
- X-linked retinoschisis (XLRS)
- Achromatopsia.

2.1 Retinitis pigmentosa (RP)

Retinitis pigmentosa (RP) is a group of chronic, progressive diseases that lead to degeneration of the rod and cone photoreceptors, and the pigmented layer of the retina (retinal pigment epithelium; RPE) (Campochiaro and Mir, 2018). While most cases are non-syndromic, people can experience RP in association with other sensory deficits (syndromic) (Campochiaro and Mir, 2018). Non-syndromic describes conditions that are present not as a result of another syndrome, whereas syndromic describes conditions which occur as a result of another syndrome. Symptoms of RP include impaired night vision (nyctalopia), a loss of peripheral vision and deteriorated central vision (Verbakel et al, 2018).

RP is inherited through autosomal dominant, autosomal recessive or X-linked patterns (Campochiaro and Mir, 2018). There are currently over 80 genes associated with RP, with

most expressed in either the photoreceptors or the RPE cells (Verbakel et al, 2018). Subtypes of RP that commence earlier in life are usually associated with faster progression, while persons with X-linked subtypes tend to experience greater disease severity (Verbakel et al, 2018).

People can undergo genetic testing to determine the presence of genetic mutations associated with RP; however, this is challenging due to significant genetic diversity (Birtel et al, 2019). Other primary diagnostic imaging techniques can be used to diagnose RP and are essential in assessing disease severity and progression (Verbakel et al, 2018).

While there is currently no cure for RP, both surgical and non-surgical (visual aids) approaches can be used to manage symptoms (Fahim et al, 2018). Gene therapy has been authorised by the European Medicines Agency for the treatment of adult and paediatric patients with vision loss due to inherited retinal dystrophy caused by confirmed biallelic RPE65 mutations and who have sufficient viable retinal cells. Gene and stem cell therapies are in the process of being explored as potential forms of treatment for RP (Fahim et al, 2018). Phase I/II trials of gene therapy in affected humans are ongoing (Kumaran et al, 2018a).

2.2 Leber congenital amaurosis (LCA)/early onset severe retinal dystrophy (EOSRD)

Leber congenital amaurosis (LCA) and early onset severe retinal dystrophy (EOSRD) comprise IRDs that are characterised by severe and early visual deterioration (Kumaran et al, 2017). EOSRD usually presents between infancy and five years of age whereas LCA presents between birth and the first few months of life (Kumaran et al, 2018b).

LCA/EOSRD is typically inherited via an autosomal recessive pattern, though an autosomal dominant inheritance pattern can occur in rare cases (Kumaran et al, 2018b). Presently, 25 genes responsible for LCA/EOSRD have been identified; accounting for 70-80% of cases (Kumaran et al, 2017).

Symptoms commonly associated with LCA/EOSRD include early-onset visual impairment, oscillations of the eye (nystagmus), slow/absent pupillary reactions, heightened light

sensitivity (photophobia), farsightedness (hyperopia) and cornea bulging (Kumaran et al, 2017). There are also a number of non-ocular symptoms associated with LCA/EOSRD such as neurodevelopmental delays, intellectual disability, autism and olfactory dysfunction (Chacon-Camacho and Zenteno, 2015).

LCA/EOSRD can be screened for through genetic testing which aims to detect pathogenic variations in the genes most commonly associated with the conditions (Kumaran et al, 2018b). Other diagnostic tools can be used to assess symptoms of LCA/EOSRD (Kumaran et al, 2018b).

Treatment of LCA/EOSRD currently focuses on symptom management such as the correction of refractive error and provision of low vision supports (Kumaran et al, 2018b). Gene therapy has been authorised by the European Medicines Agency for the treatment of adult and paediatric patients with vision loss due to inherited retinal dystrophy caused by confirmed biallelic RPE65 mutations and who have sufficient viable retinal cells.

Ongoing clinical trials aim to determine whether cone cell function can be protected using gene delivery at an early disease stage (Kumaran et al, 2018c). Stem cell therapy is also being investigated as a possible therapeutic option (Kumaran et al, 2018c).

2.3 Cone dystrophy

Cone dystrophy is a progressive IRD characterised by gradual degeneration of the cone photoreceptors (Sisk et al, 2018). Six genes are responsible for the vast majority of cone dystrophy cases; inherited in an autosomal dominant or autosomal recessive pattern (Gill et al, 2019).

Symptoms that most commonly present due to cone dystrophy include difficulties in adjusting to bright light (hemeralopia), colour vision disturbances, reduced visual acuity and nystagmus (Sisk et al, 2018). Persons with cone dystrophy present as either stable or progressively declining. The former typically present with cone dystrophy symptoms during early childhood and remain stable. Progressive cone dystrophy usually develops in late childhood or during early adulthood and worsens over time (Gill et al, 2019).

People can be screened for cone dystrophy disease-causing genes using molecular genetic testing (Gill et al, 2019). There are several diagnostic imaging techniques that can be used to diagnose cone dystrophy (Sisk et al, 2018).

There are currently no treatments available for slowing progression or restoring visual impairment. Management relies on the alleviation of visual symptoms (Gill et al, 2019).

2.4 Choroideremia

Choroideremia is an IRD that causes progressive loss of vision due to degeneration of the choroid, retinal pigment epithelium and photoreceptors (Tsang and Sharma, 2018). Choroideremia is inherited in an X-linked recessive pattern (MacDonald et al, 2015). Males are affected by X-linked recessive disorders much more frequently than females. Early disease manifests as night-blindness and peripheral visual field defects with onset typically in the first two decades of life. As the disease progresses, the visual field constricts relatively symmetrically. Visual acuity is preserved until advanced disease. Symptoms of choroideremia include tunnel vision, night blindness (nyctalopia) and can progress to central blindness (MacDonald et al, 2015).

Genetic testing can be used to screen for the presence of the choroideremia (CHM) gene mutation (MacDonald et al, 2015). Diagnosis of choroideremia is undertaken through diagnostic imaging technologies (Coussa and Traboulsi, 2012).

Current approaches to choroideremia management focus on symptom alleviation through surgical and non-surgical methods (for example, dietary modification and visual aids) (MacDonald et al, 2015). Initial clinical trial results of gene therapy have shown that rod and cone function may be restored, this potential treatment is still under investigation and, as such, is not available to the general population (Kumaran et al, 2018a; Mitsios et al, 2018).

2.5 Usher syndrome

Usher syndrome is an IRD characterised by hearing loss and deteriorating visual function. It is the leading genetic cause of deaf-blindness, representing half of all cases (Mathur and Yang, 2019). Usher syndrome is inherited in an autosomal

recessive pattern with 11 genes currently linked to the condition (Mathur and Yang, 2019).

The visual symptoms of Usher syndrome are identical to those associated with RP. These symptoms include nyctalopia, dark adaptation difficulties, abnormal electroretinography (ERG) responses, peripheral vision loss, abnormal retinal pigmentation, myopia and blindness (Mathur and Yang, 2015). People will also experience a loss of auditory function and may encounter difficulties with balance (Mathur and Yang, 2015).

Usher syndrome can be screened for the presence of chromosomal mutations most commonly associated with the disease (Mathur and Yang, 2015). Diagnosis of the condition can occur through diagnostic imaging modalities (Yang et al, 2012).

There are three major clinical subtypes of Usher syndrome. Persons with Type I (USH1) are characterised as having congenital severe-to-profound deafness, vestibular dysfunction and onset of RP within the first decade of life. While Type II (USH2) persons have congenital moderate-to-severe hearing loss, normal vestibular function and onset of RP within the second decade of life. For USH3 persons, hearing loss, vestibular dysfunction and onset of RP are progressive, sporadic and variable, respectively (Mathur and Yang, 2015).

While the auditory symptoms of the condition can be managed through the use of aid devices, there remains no treatment for the visual component of the condition (Mathur and Yang, 2019).

Viral-mediated gene replacement therapy is emerging as a potential approach to prevent a person from progressing to total blindness resulting from Usher syndrome, though the enormity of the causative genes makes their delivery difficult (Mathur and Yang, 2015; Takahashi et al, 2018).

2.6 Best disease

Best disease is an IRD characterised by a bilateral yellow lesion in the macula which changes over time (Parodi et al, 2014). Hereditary factors present as the primary risk for the condition

with disease-causing gene inherited in an autosomal dominant pattern (Budiene et al, 2014).

The symptoms associated with Best disease include slow decline in visual acuity, worsening central vision and occasionally, distorted vision of straight lines (metamorphopsia) (Zerbib et al, 2016).

Genetic testing can be used to screen for the presence of the BEST1 gene mutation (Parodi et al, 2014). Best disease can be diagnosed using imaging techniques (Budiene et al, 2014).

There are no treatments available to prevent the onset or progression of Best disease, though symptoms can be managed through the use of visual aids (Budiene et al, 2014). Clinical trials, using gene and cell-based therapies, are ongoing (Yang et al, 2015).

2.7 Cone-rod dystrophy

Cone-rod dystrophy is an IRD that is part of the group of pigmentary retinopathies characterised by progressive degeneration of the cone and rod cells (Durlu et al, 2014). The symptoms of cone-rod dystrophy include poor visual acuity, light sensitivity (photophobia), nystagmus, colour blindness (dyschromatopsia) and impaired night vision (nyctalopia) (Gill et al, 2019). Cone-rod dystrophy differs from cone dystrophy in that it is characterised by earlier degeneration of rod photoreceptors (Thiadens, 2012).

People can undergo genetic testing to determine the presence of genetic mutations associated with cone-rod dystrophy. Further, the disease can be diagnosed using various imaging techniques (Gill et al, 2019).

The prognosis of cone-rod dystrophy is typically more severe and rapid relative to other IRDs, leading to earlier total blindness. However, the age of onset varies ranging from the second to the fifth decade of life (Thiadens et al, 2012).

There are no existing treatments to prevent the progression of cone-rod dystrophy (Gill et al, 2019). Care strategies focus on alleviating the symptoms, including refractive correction, tinted lenses for photophobia and low vision aids (Gill et al, 2019).

2.8 Stargardt disease

Stargardt disease is the most prevalent inherited macular dystrophy. It is characterised by rapid deterioration of central vision and a progressive bilateral atrophy of the RPE and neuroepithelium (Tanna et al, 2017). People with the disease experience deterioration of retinal rod and cone photoreceptors, atrophy of the macular RPE, and macular degeneration (Han et al, 2014). Stargardt disease leads to a decline in central visual including an inability to perceive colours (dyschromatopsia) and the emergence of blind spots (scotoma) (Tanna et al, 2017).

ABCA4 is the primary gene associated with Stargardt disease, though there are over 900 disease-causing variants identified in the gene (Tanna et al, 2017). As the gene is inherited in an autosomal recessive pattern, hereditary factors are central to assessing the risk of disease presentation (Tanna et al, 2017).

Genetic testing for Stargardt disease is particularly difficult due to the genetic diversity of the disease (Tanna et al, 2017). Retinal imaging technologies can be used as a diagnostic tool (Ergun et al, 2015).

There is currently no treatment for Stargardt disease, though gene therapy is emerging as a potential option (Han et al, 2014; Kumaran et al, 2018a). Limiting exposure to UV light by wearing UV screening glasses and limiting intake of vitamin A is advised as part of disease management strategies. Stem cell therapies are also being investigated (Tanna et al, 2017). In addition, two late stage clinical trials investigating an oral therapy are underway (Fighting Blindness Foundation, 2019).

2.9 X-linked retinoschisis (XLRS)

X-linked retinoschisis (XLRS) is a rare congenital malformation of the retina characterised by splitting within inner retinal layers, including the nerve fibre layer (Rao et al, 2018). The primary risk factor for XLRS is the RS1 gene, which is inherited in an X-linked manner (Sieving et al, 2014).

XLRS is characterised by central vision loss, nystagmus and/or strabismus (crossed eyes). More severe cases will exhibit symptoms of vitreous haemorrhage, retinal detachment and/or

glaucoma, which can result in extensive vision loss (Vincent et al, 2013).

Diagnosis of XLRS can be made using retinal imaging techniques (Vincent et al, 2013; Sieving et al, 2014). Presently, no cure exists for XLRS but gene replacement therapy is being explored (Kumaran et al, 2018a).

Management of XLRS generally relies on pharmacological or vision-aid interventions (Molday et al, 2012). Surgical options may also be utilised to address more severe complications associated with the condition, such as retinal detachment (Rao et al, 2018).

2.10 Achromatopsia

Achromatopsia is an inherited macular dystrophy characterised by dysfunction or the absence of cone photoreceptors (Yu et al, 2014). While most people experience complete achromatopsia, with no function present in all cones, some people have incomplete achromatopsia in which one or more cone types remains functional (Kohl et al, 2018).

Achromatopsia is diverse with people displaying a range of symptoms; however, the primary symptom is a partial or total absence of colour vision (Hirji et al, 2018). Other symptoms may include photophobia, nystagmus, and poor visual acuity (Hirji et al, 2018).

The genes associated with achromatopsia are inherited in an autosomal recessive pattern indicating that hereditary factors are most significant risk factor for the condition (Kohl and Hammer, 2013). Achromatopsia can be screened for using molecular genetic testing approaches (Kohl et al, 2018). Diagnosis can occur using a variety of imaging techniques (Kohl et al, 2018).

While there is currently no cure for achromatopsia, early phase clinical trials are currently being undertaken to determine the extent to which gene therapy might benefit visual acuity, colour discrimination, photophobia and nystagmus (Kumaran et al, 2018a). Strategies available to manage the symptoms associated with the condition include the use of special-filter glasses and low vision aids (Kohl et al, 2018).

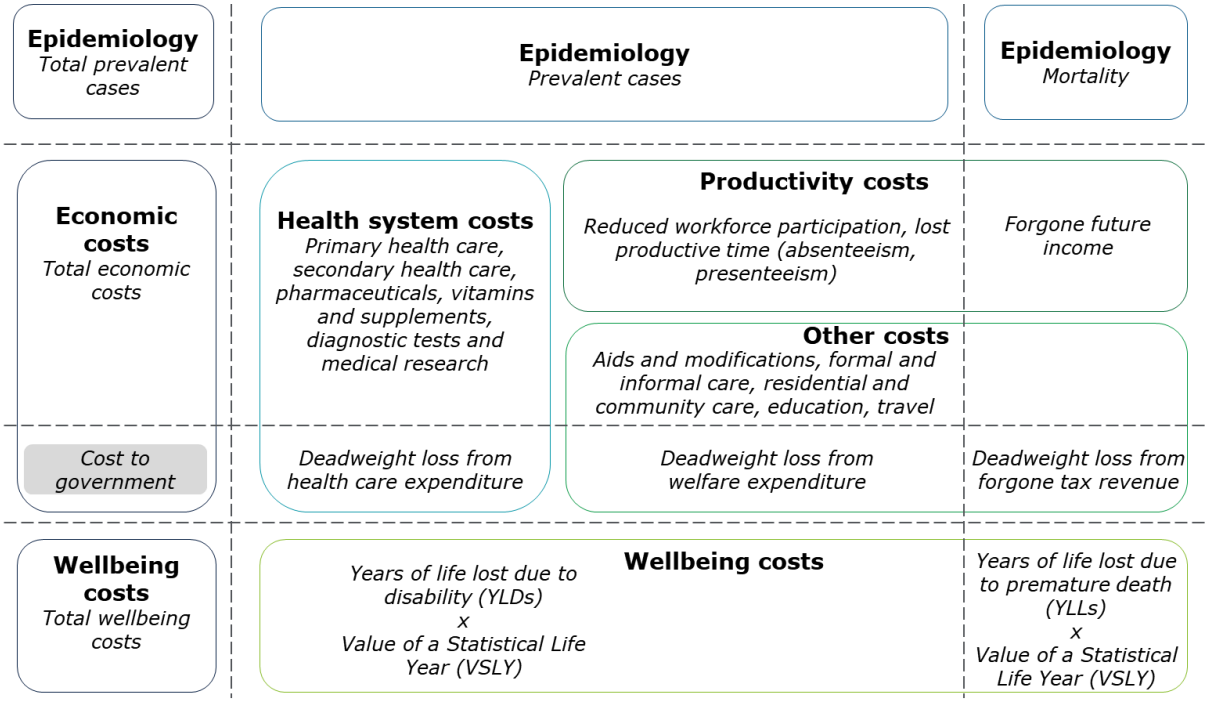
3 Methodology

This section describes the cost-of-illness methodology used to estimate the socioeconomic burden of IRDs in the RoI in 2019.

The socioeconomic burden of IRDs in the RoI was estimated using cost-of-illness methodology applying a prevalence approach (Larg & Moss, 2011).

This approach involves estimating the number of persons living with an IRD in a base period (2019) and the costs attributable to IRDs in that period. Figure 3.1 below provides an overview of the cost-of-illness model. The analysis was based on a targeted literature review and primary data (survey) collection, described in the following sub-sections.

Figure 3.1: Cost-of-illness model overview



Source: Deloitte Access Economics.
Note: There is a lack of available data on the risk of premature mortality attributable to IRDs. As such, no costs associated with premature mortality were estimated.

3.1 Costing methodology

Costs were categorised by type, as:

- Costs to the health system including primary and secondary health care, pharmaceuticals, vitamins and supplements, diagnostic tests and medical research.
- Individual productivity losses due to reduced workforce participation, absenteeism and presenteeism (reduced productivity while at work).
- Other costs such as aids and modifications, formal and informal care, residential and community care, education, travel and deadweight losses (society-wide efficiency losses arising from loss of taxation revenue due to reduced workforce participation and higher government expenditures).
- Loss of wellbeing measured by years of healthy life lost to IRDs.

Different costs of disease are borne by different individuals or sectors of society. Understanding how costs are shared helps to make informed decisions regarding interventions. While persons living with an IRD are most severely affected by the condition, family members and other parts of society also face costs attributable to IRDs.

This analysis estimated first round societal impacts. No second round or longer term dynamic impacts were modelled (i.e. changes in wages or labour market outcomes associated with the economic burden of IRDs).

Component figures or calculations may not sum to totals due to rounding.

3.2 Targeted literature review

A targeted review of the scientific literature and publicly available databases was conducted to identify the most relevant inputs for this report. The review involved a targeted (non-systematic) search of the PubMed and Cochrane Library databases to:

- Identify the target indication (IRDs)
- Identify epidemiological parameters of the target indication
- Identify economic parameters of the target indication.

Additional ad-hoc searches were performed, as required. Where possible, inputs specific to IRDs and the RoI were used. Where this was not possible, inputs from similar populations in other countries, and diseases of comparable severity and symptoms, but different aetiology, were used.

3.3 Primary data (survey) collection and analysis

A survey was distributed to persons living with an IRD and/or the parents of children (under 18) living with an IRD to:

- Collect more specific and detailed primary data regarding the health care resource utilisation and productivity impacts of persons living with an IRD and the parents of children (under 18) living with an IRD, attributable to IRDs.
- Address any data gaps identified in the targeted literature review.

Retina International and the IRD COUNTS consortium identified relevant stakeholders for recruitment. Participation was restricted to persons living with an IRD and the parents of children (under 18) living with an IRD. Ethical and patient consent procedures complied with all requirements set out in the European Union General Data Protection Regulations (GDPR), and ethical and compliance obligations. Please refer to section 4 for a breakdown of persons living with an IRD and/or the parents of children (under 18) living with an IRD invited to complete the survey, and responses received.

The survey questionnaire was co-designed with Retina International and the IRD COUNTS consortium, and with reference to the metrics identified in the targeted literature review. Skip logic was incorporated into the programming of the survey to ensure only relevant questions would be asked of participants, depending on the answers provided to previous questions.

Survey responses were cleaned for inappropriate responses including attributing other related costs in questions about specific cost items. For example, referring to travel costs when attending the doctor, travel costs are separately captured in specific questions and, hence, these responses were removed to avoid double counting. Each free text question was further analysed for response variance, outliers were removed and

response from the UK and RoI were pooled to reduce variance were appropriate.

3.4 Sensitivity analysis

In many cases, the inputs underlying the cost-of-illness analysis are uncertain and changes in these inputs may have a significant impact upon the total estimate of the costs of IRDs in the RoI in 2019. Published population prevalence estimates of IRDs (overall or condition-specific) are limited. Recent and nationwide prevalence estimates for IRDs in the RoI were not identified.

Given the limited published data on the prevalence of IRDs in the RoI, sensitivity analysis using an upper bound sensitivity estimate based on the highest published prevalence estimate available was undertaken. Section 10 outlines the sensitivity of the costs of IRDs in the RoI in 2019 to this upper bound prevalence estimate.

4 Survey results

This section describes the respondent characteristics from the survey of persons living with an IRD and/or the parents of children (under 18) living with an IRD in the RoI.

Key findings

- Male RoI respondents comprised a slight majority (male: 54.0%, female: 46.1%).
- Approximately two thirds of responses were received from adults aged 18 and older.
- The sample was slightly skewed towards older (aged 35 years and older) respondents who make up 53.9 per cent of the sample.
- Just over half (59.2%) of survey participants reported they had received a genetic test for the purpose of diagnosing their IRD.
- Most persons living with an IRD (69.7%) reported at least one member of their family had seen a specialist to check for IRD symptoms.

4.1 Summary of approach

A survey was administered to persons living with an IRD and/or the parents of children (under 18) living with an IRD to:

- Collect more specific and detailed primary data regarding the health care resource utilisation and productivity impacts of persons living with an IRD, and the parents of children (under 18) living with an IRD attributable to IRDs.
- Address any data gaps identified in the targeted literature review.

129 survey responses were received from persons living with an IRD and parents of children (under 18) living with an IRD across the RoI and UK.

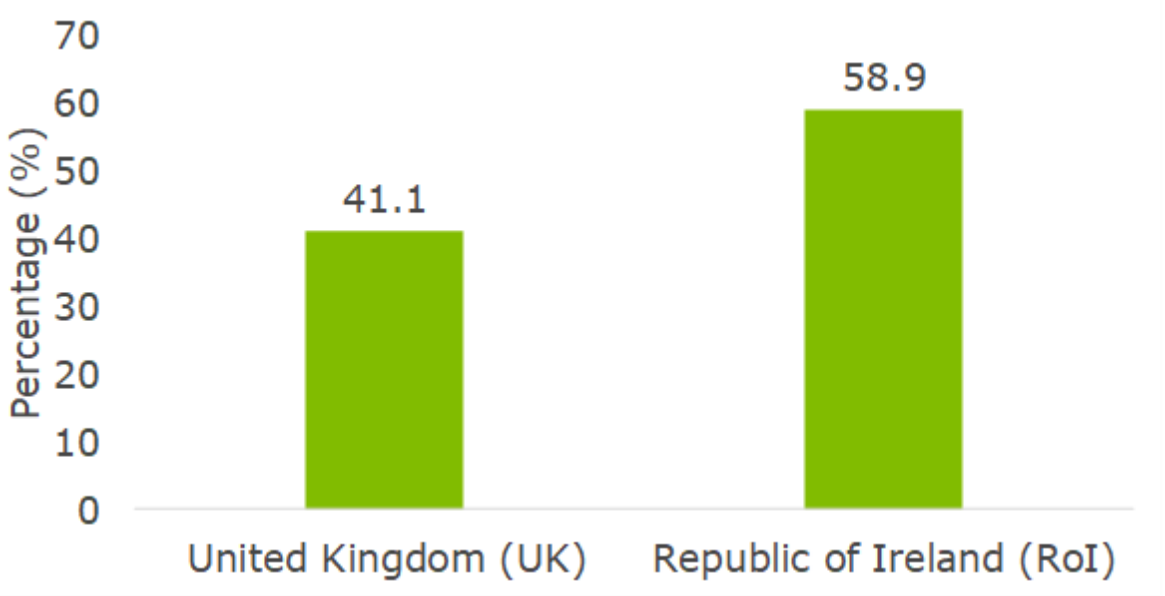
Please refer to Section 3.3 for more detail regarding the survey methodology.

4.2 Participant characteristics

Of the 129 people who responded to the survey, 58.9% were from the RoI and 41.1% were from the UK (Chart 4.1 and Table 4.1).

The remainder of this section reports the characteristics of survey participants from the RoI.

Chart 4.1: Distribution of survey participants by country (n=129)



Source: Deloitte Access Economics analysis.

Table 4.1: Distribution of survey participants by country (n=129)

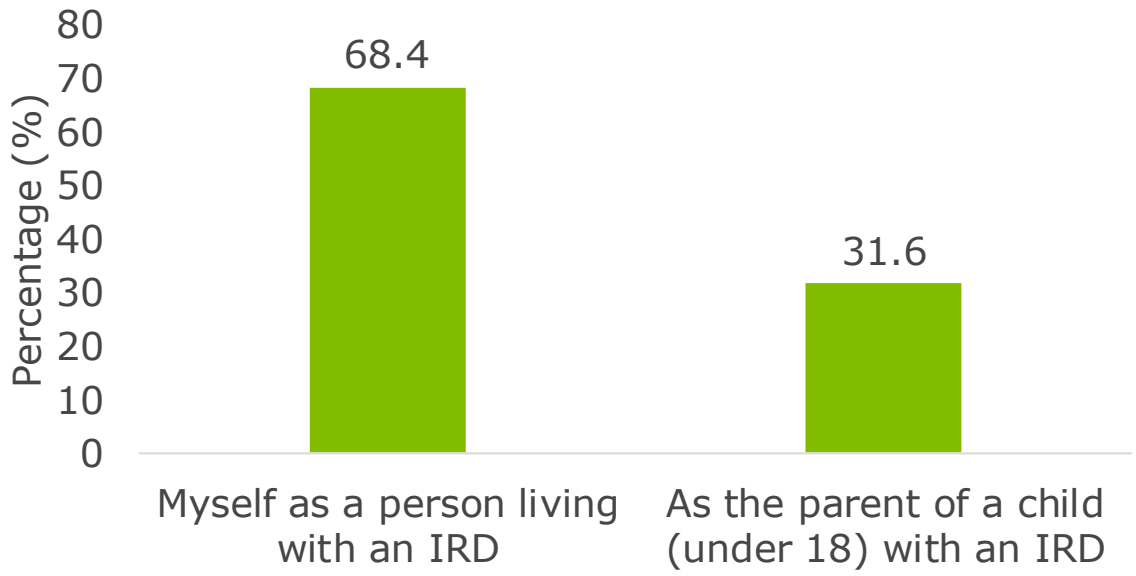
Country	Count (n)	Percentage (%)
United Kingdom (UK)	53	41.1
Republic of Ireland (RoI)	76	58.9
Total	**129**	**100.0**

Source: Deloitte Access Economics analysis.

4.2.1 Participant type (person living with an IRD or parent of a child with an IRD)

Of the 76 RoI respondents, 68.4% were persons living with an IRD and 31.6% were the parents of children (under 18) living with an IRD (Chart 4.2 and Table 4.2).

Chart 4.2: Distribution of RoI survey participants by type (person living with an IRD or parent of a child with an IRD) (n=76)



Source: Deloitte Access Economics analysis.

Table 4.2: Distribution of RoI survey participants by type (person living with an IRD or parent of a child with an IRD) (n=76)

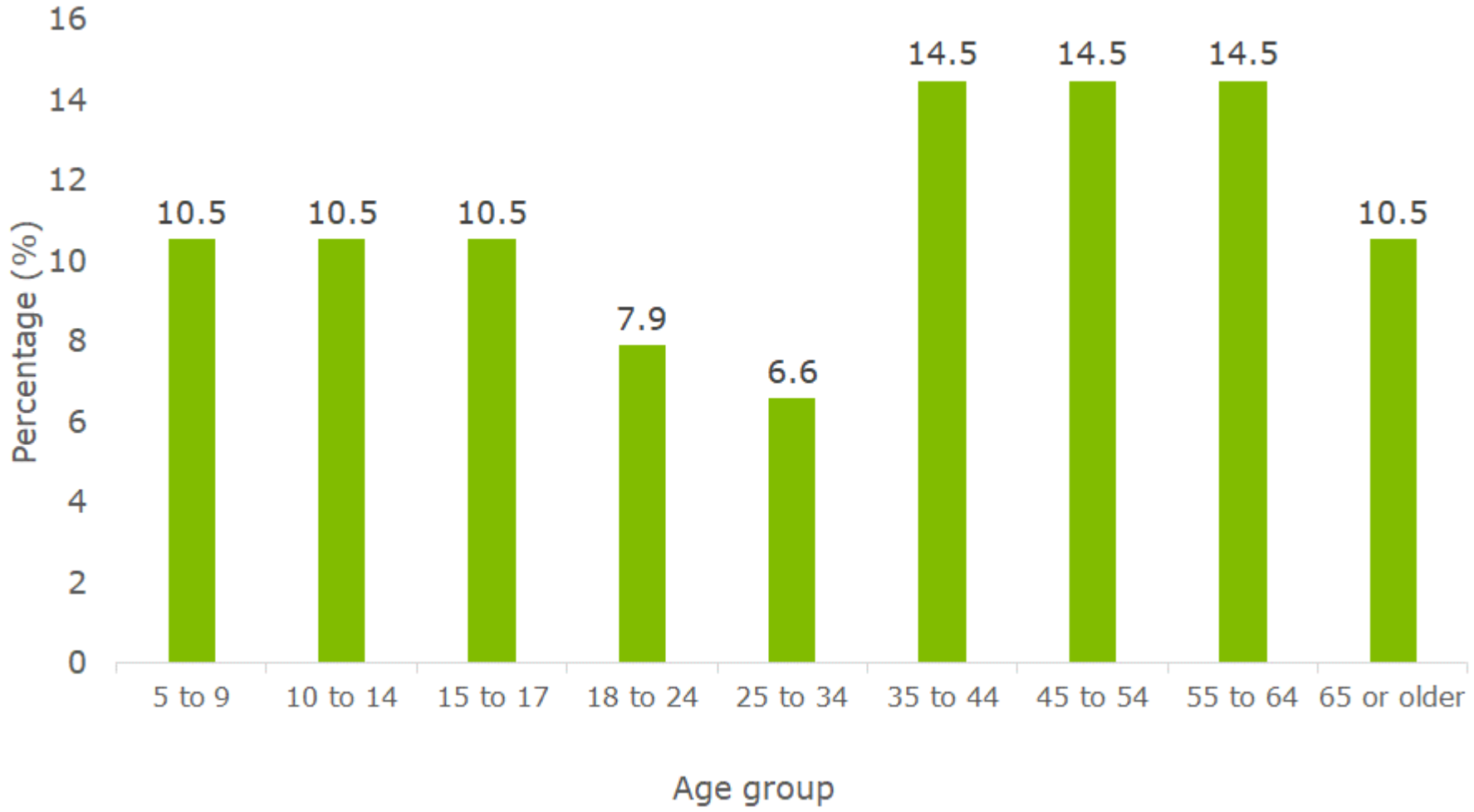
Participant type (Adult or Parent)	Count (n)	Percentage (%)
Myself as a person living with an IRD	52	68.4
As the parent of a children (under 18) living with an IRD	24	31.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

4.2.2 Age

The survey sample is skewed towards older persons living with an IRD with the majority of RoI respondents aged 45 years and older (Chart 4.3 and Table 4.3). Younger adults, aged 18 to 24 (7.9%) and 25 to 34 (6.6%) were noticeably smaller groups in the survey.

Chart 4.3 Distribution of RoI survey participants by age (n=76)



Source: Deloitte Access Economics analysis.

Table 4.3: Distribution of RoI survey participants by age (n=76)

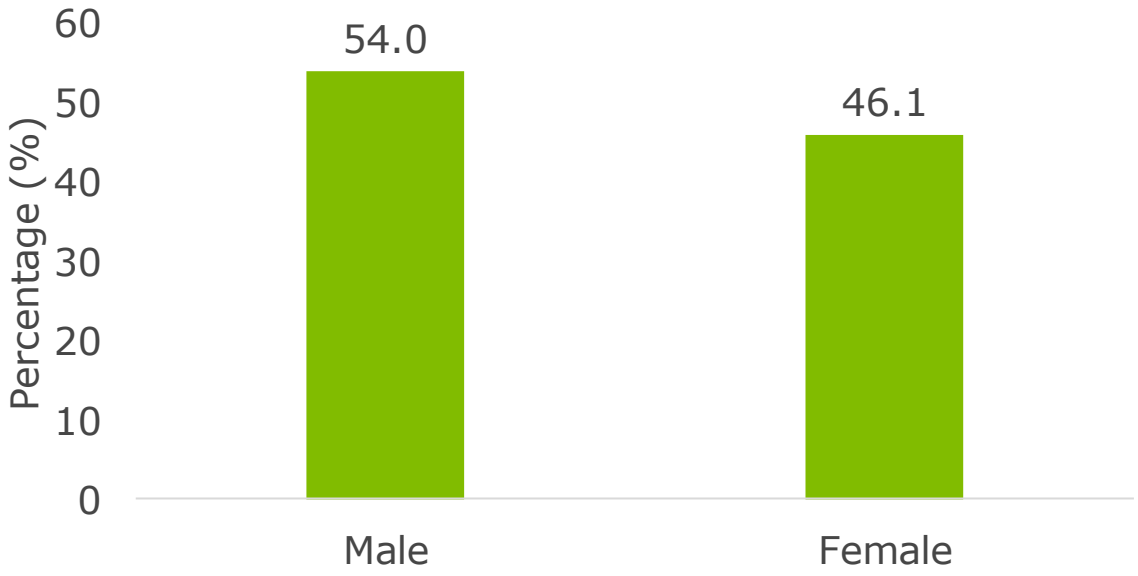
Age group	Count (n)	Percentage (%)
5 to 9	8	10.5
10 to 14	8	10.5
15 to 17	8	10.5
18 to 24	6	7.9
25 to 34	5	6.6
35 to 44	11	14.5
45 to 54	11	14.5
55 to 64	11	14.5
65 or older	8	10.5
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

4.2.3 Sex

Male RoI respondents comprised a slight majority (male: 54.0%, female: 46.1%) (Chart 4.4 and Table 4.4).

Chart 4.4: Distribution of RoI survey participants by sex (n=76)



Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

Table 4.4: Distribution of RoI survey participants by sex (n=76)

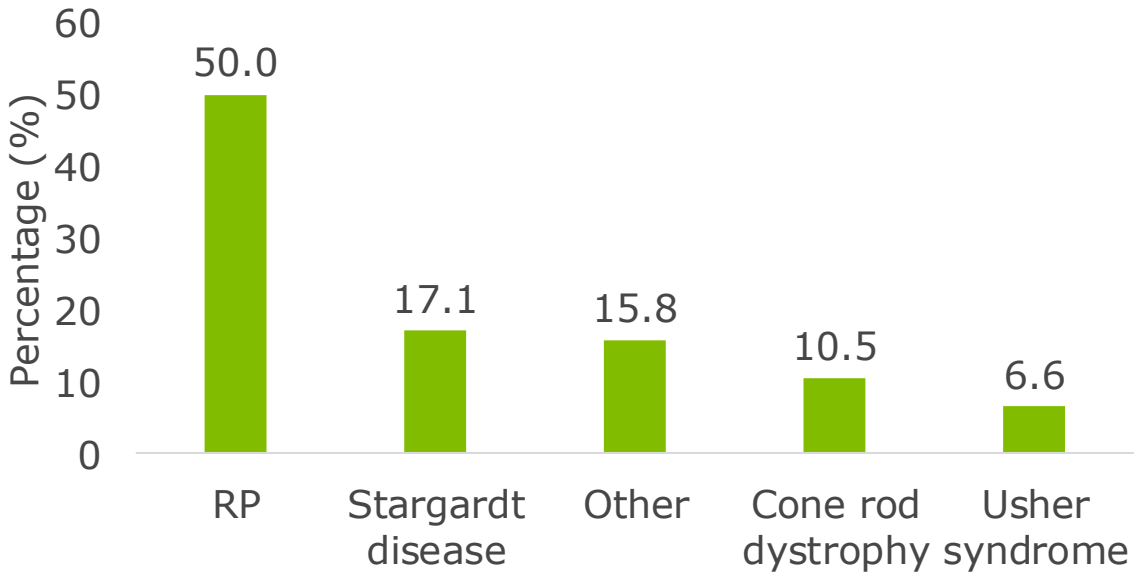
Sex	Count (n)	Percentage (%)
Male	41	54.0
Female	35	46.1
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

4.2.4 Condition

Survey respondents with RP made up half of the sample (50.0%), followed by Stargardt disease (17.1%), other conditions (15.8%), cone-rod dystrophy (10.5%) and Usher syndrome (6.6%). The other conditions included achromatopsia, cone dystrophy, choroideremia, LCA and XLRS (Chart 4.5 and Table 4.5). There were no responses for Best disease.

Chart 4.5: Distribution of survey participants by condition in the RoI (n=76)



Source: Deloitte Access Economics analysis.

Table 4.5: Distribution of survey participants by condition in the RoI (n=76)

IRD	Count (n)	Percentage (%)
RP	38	50.0
Stargardt disease	13	17.1
Other	12	15.8
Cone rod dystrophy	8	10.5
Usher syndrome	5	6.6
Total	**76**	**100.0**

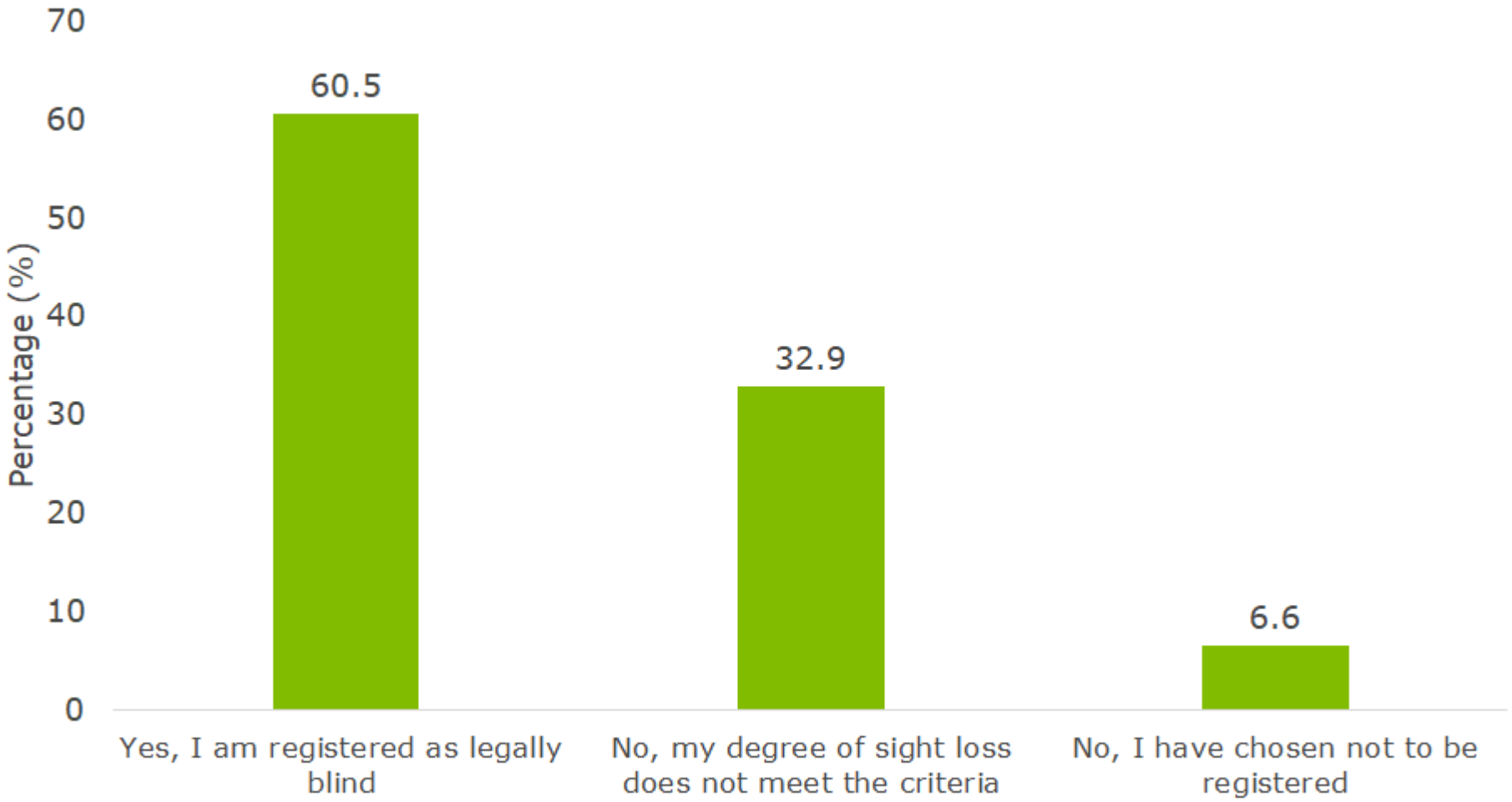
Source: Deloitte Access Economics analysis.

4.2.5 Legally blind status

Most survey participants in the RoI were registered as legally blind (60.5%) (Chart 4.6 and Table 4.6).[1] A small proportion (6.6%) of respondents indicated they had chosen not to register as legally blind.

[1] Legally blind was defined as 'your best corrected visual acuity is equal to or less than 6/60 in the better eye or your field of vision is limited, the widest diameter of vision subtending an angle of not greater than 20 degrees'.

Chart 4.6: Distribution of RoI survey participants by legal blindness status (n=76)



Source: Deloitte Access Economics analysis.

Table 4.6: Distribution of RoI survey participants by legally blind status (n = 39)

Legally blind status	Count (n)	Percentage (%)
Yes, I am registered as legally blind	46	60.5
No, my degree of sight loss does not meet the criteria	25	32.9
No, I have chosen not to be registered	5	6.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

4.2.6 Genetic testing

In some instances, persons living with an IRD can receive a genetic test to investigate the underlying genetic cause(s) of their specific IRD. Just over half (59.2%) of survey participants reported they had received a genetic test for the purpose of diagnosing their IRD. (Chart 4.7 and Table 4.7).

Chart 4.7: Genetic test utilisation of survey participants in the RoI (n=76)

Source: Deloitte Access Economics analysis.

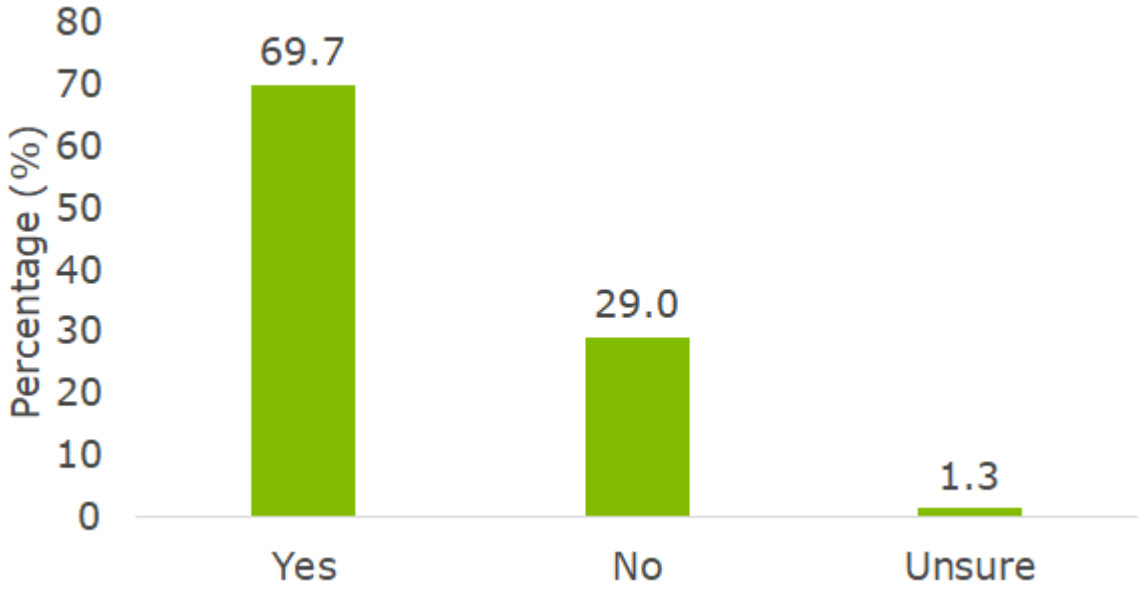
Table 4.7 Genetic test utilisation of survey participants in the RoI (n=76)

Genetic test status	Count (n)	Percentage (%)
Had a genetic test	45	59.2
Not tested	31	40.8
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Most persons living with an IRD (69.7%) reported at least one member of their family had seen a specialist to check for IRD symptoms. (Chart 4.8 and Table 4.8).

Chart 4.8: Distribution of familial access to specialist care in the RoI (n=76)



Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

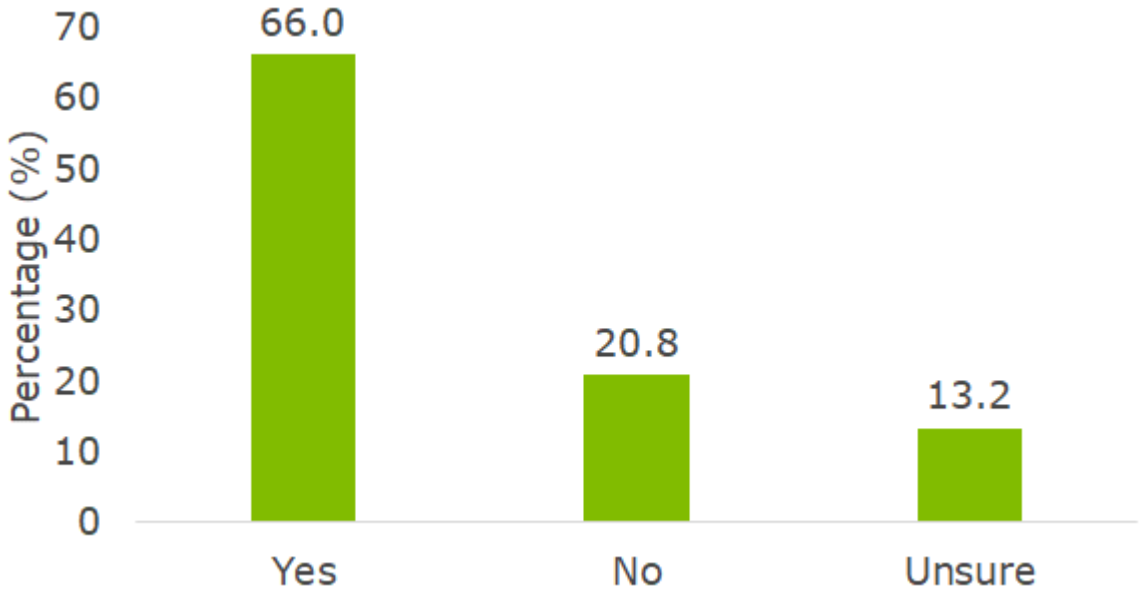
Table 4.8: Distribution of familial access to specialist care for IRDs in the RoI (n=76)

Family has sought specialist advice	Count (n)	Percentage (%)
Yes	53	69.7
No	22	29.0
Unsure	1	1.3
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

66 per cent of respondents who had family members who sought specialist advice also received a genetic test. (Chart 4.9 and Table 4.9)

Chart 4.9: Distribution of familial access to genetic testing in the RoI (n=53)



Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

Table 4.9: Distribution of familial access to genetic testing for IRDs in the RoI (n=53)

Family genetic test	Count (n)	Percentage (%)
Yes	35	66.0
No	11	20.8
Unsure	7	13.2
Total	**53**	**100.0**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to 100% due to rounding.

5 Prevalence

The prevalence of IRDs refers to the proportion of a population who have IRDs in a given time period. This section describes the approach and findings of the prevalence of IRDs by age and sex in the RoI in 2019.

Key findings

- The overall prevalence of IRDs was estimated to be 0.03% which represented 1,522 cases in the RoI in 2019.
- Across the 10 IRDs included in this analysis, RP contributed the highest proportion of cases at 49.6%, or 755 cases in the RoI.
- The lowest proportion of cases was for choroideremia (1.4%) with 22 cases in the RoI.
- Prevalence of IRDs was estimated to be slightly higher in males (52.4%) and tended to increase with age, up to the 60-69 year age group.

5.1 Summary of approach

Published population prevalence estimates of IRDs (overall or condition-specific) are limited. Recent and nationwide prevalence estimates for IRDs in the RoI were not identified. National registry data on the prevalence of five out of the 10 IRDs was identified from a population-based study conducted in Denmark (Bertelsen et al, 2014). This included a prevalence estimate of RP, LCA/EOSRD, cone-rod dystrophy, choroideremia, and Usher syndrome. In addition, an observational study of Best disease conducted in Denmark informed the estimated population prevalence of Best disease in the RoI (Bitner et al, 2012).

To estimate the prevalence of the remaining IRDs (cone dystrophy, Stargardt disease, XLRS, and achromatopsia) included in this analysis, the relative prevalence of the identified IRDs was derived from published results of the Target 5000 study conducted in the RoI and applied to the

relative prevalence of the remaining IRDs (Dockery et al, 2017; Bocquet et al, 2013).

Age and sex specific prevalence rates for the IRDs were utilised where they were available, from the literature. Data from the eyeGENE registry, which reports on a sample of 4,635 participants with various IRDs in the United States, was used to inform the sex distribution in the absence of condition-specific literature (National Eye Institute, 2019).

The number of IRD cases in the RoI in 2019 was estimated by applying prevalence rates to population data sourced from the Central Statistics Office (CSO).

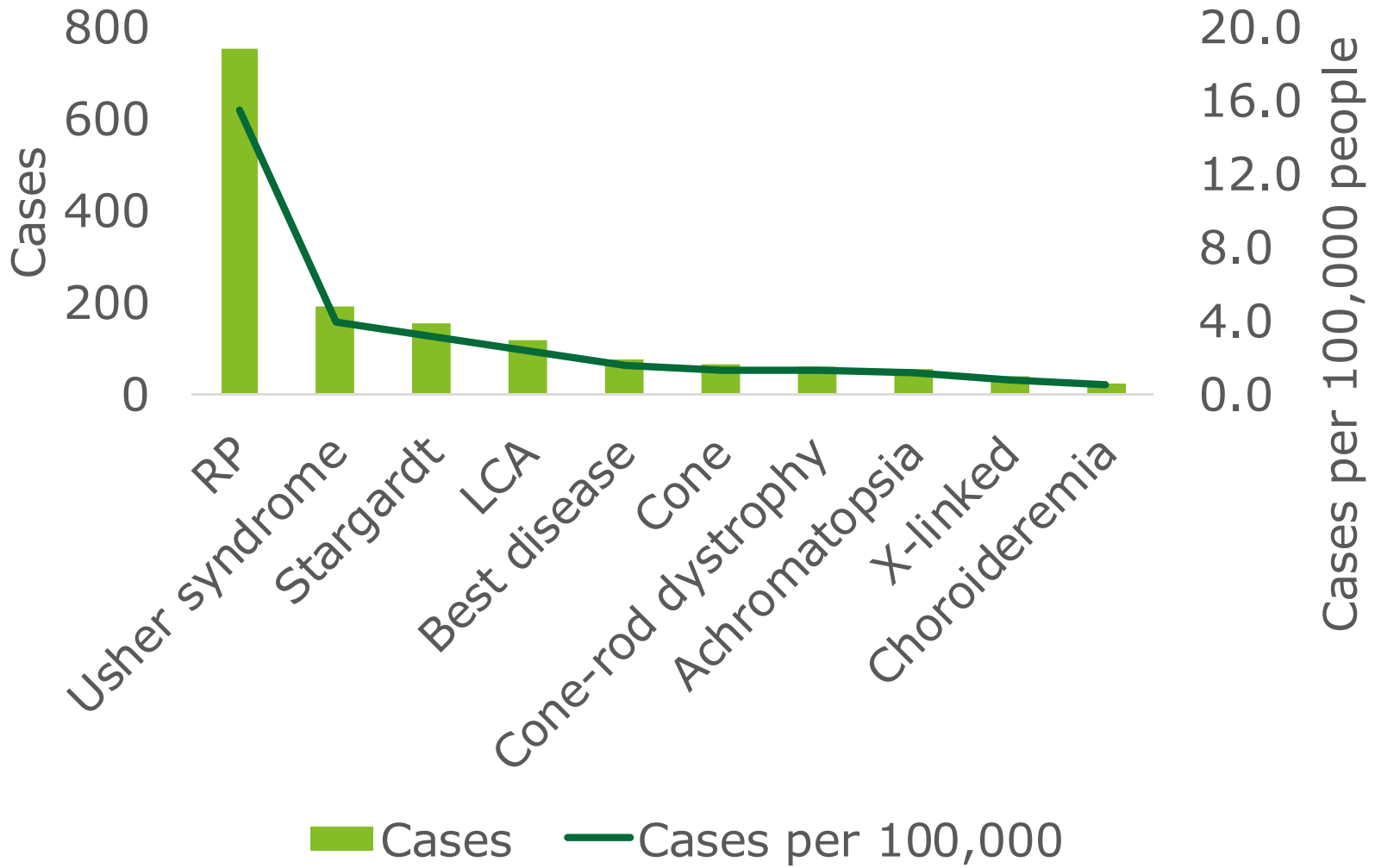
Please refer to Appendix B for further detail regarding the sources informing overall prevalence, and age and sex distribution estimates by condition.

5.2 Results

Overall, the prevalence of IRDs in the RoI was estimated at 0.03% or 1,522 prevalent cases in 2019. The highest proportion of the overall prevalence was attributed to RP (49.6%, 755 people), followed by Usher syndrome (12.4%, 189 people). Table 5.1, Chart 5.2 and Table 5.1 provide detailed prevalence estimates by condition, including the prevalence rate, number of cases, and proportion represented by each condition.

Overall prevalence of IRDs in the RoI by age and sex is shown in Chart 5.2. The prevalence rate of IRDs increases progressively with age until the 60-69 year age group, after which prevalence gradually declines. Overall prevalence is slightly higher in males (52.4%) compared to females (47.6%).

Chart 5.1: Prevalence of IRDs in the RoI (2019) by condition



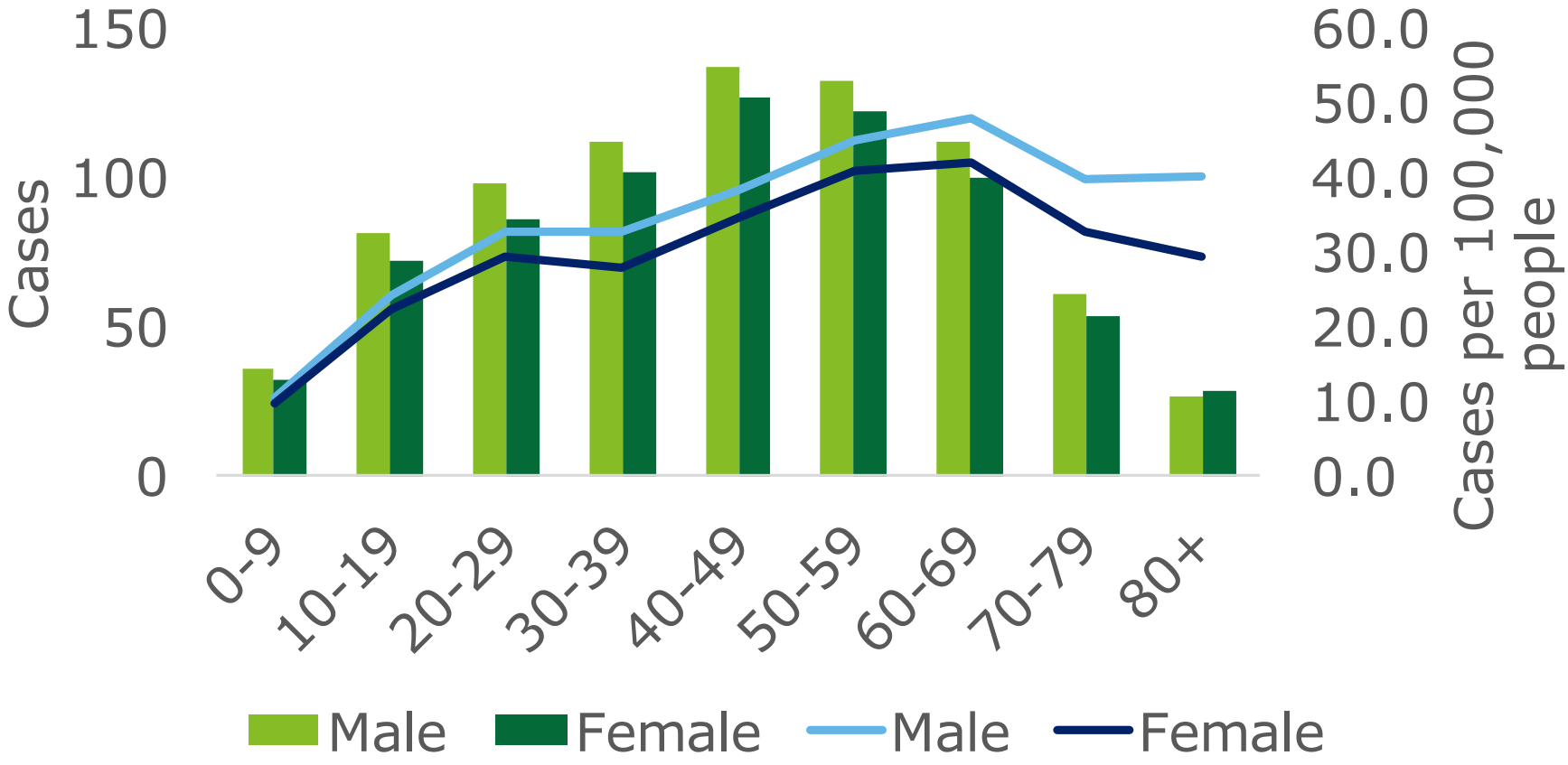
Source: Deloitte Access Economics analysis.

Table 5.1: Prevalence of IRDs in the RoI (2019) by condition

IRD	Rate (%)	Cases	Proportion (%)
RP	0.0154	755	49.6
Usher syndrome	0.0039	189	12.4
Stargardt disease	0.0032	154	10.1
LCA/EOSRD	0.0024	116	7.6
Best disease	0.0015	73	4.8
Cone dystrophy	0.0013	64	4.2
Cone-rod dystrophy	0.0012	59	3.9
Achromatopsia	0.0011	54	3.5
XLRS	0.0007	35	2.3
Choroideremia	0.0004	22	1.4
Total IRDs	**0.0311**	**1,522**	**100.0**

Source: Deloitte Access Economics analysis based on published literature.
Note: Components may not sum to totals due to rounding.

Chart 5.2: Prevalence of IRDs in the RoI (2019) by age and sex



Source: Deloitte Access Economics analysis.

6 Health system costs

This section describes the approach used to estimate the health system costs – including primary and secondary health care, diagnostic tests, pharmaceuticals, vitamins and supplements, and medical research – associated with IRDs in the RoI in 2019.

Key findings

- Total health system costs associated with IRDs in the RoI in 2019 were estimated to be €2.2 million.
- The largest components of health system costs were secondary health care (€0.8 million), followed by primary health care (€0.7 million) and diagnostic tests (€0.4 million).

6.1 Summary of approach

Health system costs include primary and secondary care, diagnostic tests, pharmaceuticals, vitamins and supplements, and medical research. Health system costs in the RoI are primarily paid for by government; however, other sources include out-of-pocket patient payments and funding from other parties such as private health insurers.

The targeted literature review identified no sources estimating the health system cost of IRDs in the RoI. International literature was also scarce. The approaches and evidence for estimating categories of health system costs are described in each subsection below. Where available, utilisation of health services was derived from country specific survey results and unit costs were sourced from national reference prices.

While survey data collected provides an estimate of out-of-pocket expenditures, it does not provide a method for attributing costs between society, government, family members and the individual. For this reason, the breakdown of cost by payer was based on the OECD (2017) who publish an estimated share of health system costs borne by the

government, compulsory health insurance, out-of-pocket, voluntary health insurance and other.

6.2 Primary health care

Primary health care includes general practitioner (GP) visits, allied health services, and other community-based services.

Primary health system costs were estimated by applying the average utilisation of primary health care services to the incremental unit cost of each service. Average utilisation was estimated using country specific survey data of the proportion of the IRD population accessing each service and the annual per-person frequency of service use. Out-of-pocket travel costs for each service were also obtained from the survey results. Where possible, incremental unit costs were sourced from national reference prices.

6.2.1 Utilisation of primary health care services

In order to inform the utilisation of health services among persons living with an IRD, data was taken from the country specific survey results. Health services accessed by respondents in the past 12 months included an optometrist (11%), habilitation specialist (4%)[2], sight support volunteer (4%), GP (8%), genetic counsellor (7%), psychologist (7%), eye clinic liaison officer (3%), and occupational therapist (1%) (Table 6.1).

Survey data was also used to inform the annual frequency of health service use among persons living with an IRD. The most commonly visited services included psychologists (18.3 times per annum), eye clinic liaison officers (3.0 times per annum), sight support volunteers (1.5 times per annum), and GPs (1.5 times per annum) (Table 6.1).

[2] Habilitation involves one-to-one training for children and young people with a vision impairment, it aims to develop their personal mobility, navigation and independent living skills (Wall, 2017).

Table 6.1: Health service utilisation of survey participants in the RoI (n=76)

Health system service	Percentage (%) accessing service	Number of visits per year
GP	8	1.5
Optometrist/optician	21	1.0
Eye clinic liaison officer	3	3.0
Sight support volunteer	4	1.5
Psychologist, psychiatrist or counsellor	7	18.3
Genetic counsellor	7	1.0
Occupational therapist	1	1.0
Habilitation, rehabilitation specialist or service, or low vision specialist	4	1.3

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages did not sum to 100.

6.2.2 Incremental unit costs of primary health care services

The incremental unit cost for each service was assumed to comprise a reimbursed amount, out-of-pocket expenditure, and travel costs. Where possible, the reimbursed amount for each service was estimated based on national reference prices (HSE, 2018; HSE, 2019).

For a range of services, including eye clinic liaison officers, habilitation specialists, occupational therapists, psychologists, and sight support volunteers, an average hourly service cost was estimated based on annual salary data published by the

HSE (2019), adjusted for annual leave entitlements and non-wage costs (Rabiee et al, (2015).

The cost of counselling was based on an industry survey conducted in 2018 based on prices charged by Irish Association for Counselling and Psychotherapy (IACP) members. For genetic counselling, there was no country-specific data located. As such, the service cost was based on the UK value and converted using PPP. This approach is in line with widely used academic convention and health technology assessment guidelines in the RoI.

Out-of-pocket expenditures and out-of-pocket travel costs for each service were taken from survey responses. Where relevant, a measure of health inflation was utilised to convert unit values to 2019 terms.

Incremental health resource unit costs by service type are provided in Table 6.2.

Table 6.2: Primary health care service incremental unit costs (€ 2019)

Health system service	Average unit cost
GP	62
Optometrist/optician	118
Eye clinic liaison officer	52
Sight support volunteer	71
Psychologist, psychiatrist or counsellor	105
Genetic counsellor	215
Occupational therapist	71
Habilitation, rehabilitation specialist or service, or low vision specialist	65

Source: Deloitte Access Economics analysis.

The average primary health care cost for persons living with an IRD is summarised in Table 6.3.

Table 6.3: Average cost of primary health care per person with an IRD (€ 2019)

Service	Cost
Average primary health care costs per person with an IRD	252

Source: Utilisation from Deloitte Access Economics IRD survey. Unit costs from HSE (2018), HSE (2019), HSE (2019b), IACP (2018), Gene Health UK (2019), Baxter and Rabiee (2015),

Organization for Economic Cooperation and Development (OECD) (2018).

6.3 Secondary health care

Secondary health care includes hospital inpatient and outpatient services. Inpatient services include inpatient hospitalisations related to a primary or secondary diagnosis of an IRD, and falls attributable to IRDs. Outpatient services include ophthalmologist attendances and associated procedures performed in an outpatient clinic. The cost of falls attributable to IRDs was also estimated.

The total cost associated with secondary health care services was estimated by applying the average cost of services to the number of services delivered.

6.3.1 Inpatient services

In the absence of country-specific admissions data by ICD-10 code, the hospitalisation rate associated with IRDs in the UK was applied to the RoI population. A similar approach was used for secondary cause hospitalisations, with adjustment made to account for the number of comorbidities (2.26) based on Frick et al (2012).

The estimated number of admissions relating to IRDs as a primary cause came to 8 in total, with a further 102 admissions relating to IRDs as a secondary cause. This yielded a total of 110 admissions attributable to IRDs in 2019.

The average cost of an admission was calculated by taking an average of retinal procedure costs weighted by the relative frequency of each code (HSE, 2019). For secondary cause admissions, a weighted average cost was calculated based on eye procedure codes. The estimated cost averaged €4,311 for primary cause admissions, and €4,277 for secondary cause admissions.

To estimate the total cost of inpatient services, the estimated number of admissions was applied to the average cost of an admission. The estimated cost totalled €471,185.

6.3.2 Outpatient services

The number of outpatient services attributable to IRDs was estimated by applying the average utilisation of outpatient

services per person, derived from country specific survey results, to the number of prevalent cases. In the absence of country-specific data, an average cost for a specialist ophthalmologist consult in an outpatient clinic (code 130) was sourced from the NHS (2018a) National Schedule of Reference Costs, converted to RoI terms using purchasing power parity (PPP) and then inflated to 2019 terms (OECD, 2018)[3].

Out-of-pocket expenditures and travel costs were taken from the survey responses and added to the average service cost to estimate the total incremental unit cost. Average secondary health care (outpatients) costs per person are shown in Table 6.4.

Table 6.4: Average cost of outpatient health care per person with an IRD (2019)

Parameter	Source	Estimate
Percentage (%) accessing service	Deloitte Access Economics survey	100
Number of times per year	Deloitte Access Economics survey	1.2
Incremental unit cost of outpatient consultation (€)	NHS (2018a), Deloitte Access Economics survey	65
Total average annual cost of outpatient services (€) per person with an IRD		47

Source: Deloitte Access Economics analysis, NHS (2018a).

[3] The Ready Reckoner (2013) reports a maximum cost of cross-border consults. It was considered that this does not reflect a contemporary measure of the average cost of ophthalmology specific outpatient services.

6.3.3 Cost of falls

Falls may result from the visual impairment associated with IRDs. In order to estimate the cost of these falls, a population attributable fraction approach was used to estimate the proportion of attributable falls (Healthcare Pricing Office, n.d.). An average cost was then estimated (Gannon et al., 2007) and inflated to 2019 terms (OECD, 2018).

6.3.4 Average cost of secondary health care

The average secondary health care cost for persons living with an IRD is summarised in Table 6.5.

Table 6.5: Average cost of secondary health care per person with an IRD (€ 2019)

Service	Cost
Average secondary health care costs per person with an IRD	1,117

Source: Bocquet et al (2013), Office of National Statistics (ONS) (2019), NHS (2018a), NHS (2019b), HSE (2019), Deloitte Access Economics analysis.

6.3.4.2 Average cost of secondary health care for family members

The cost of secondary health care for family members of persons living with an IRD was assumed to include the cost of specialist outpatient consultation and genetic counselling. Survey data was used to inform the proportion of persons with an IRD whose family members had accessed these services, as shown in Table 6.6.

The number of family members accessing specialist consultation was estimated by calculating the number of persons with an IRD who reported having one or more family members who had accessed specialist consultation. It was then assumed that one of these family members had accessed this service within the past year.

To derive the number of family members accessing genetic counselling, it was assumed that family members accessed this

service in-line with the ratio of genetic counselling utilisation to genetic testing utilisation among persons with an IRD.

Family members were assumed to access one service per annum. Incremental unit costs for genetic counselling and specialist outpatient consultation were assumed to equal the respective unit costs for these services among people with an IRD.

Table 6.6: Average cost of secondary health care for family members per person with an IRD (£, 2019)

Service	Estimate
Proportion of people with an IRD whose family member received genetic counselling	33.0%
Proportion of people with an IRD whose family member received a specialist consultation	69.7%
Average secondary health care costs for family members per person with an IRD	67

Source: Utilisation from Deloitte Access Economics IRD survey. Unit costs from HSE (2018), Baxter and Rabiee (2015), Organization for Economic Cooperation and Development (OECD) (2018), Bocquet et al (2013), Office of National Statistics (ONS) (2019), NHS (2018a), NHS (2019b), HSE (2019), Deloitte Access Economics analysis.

6.4 Diagnostic tests

In the absence of sufficient country-specific data, the cost of genetic testing for persons with an IRD was estimated at €963.11 based on the average cost of retinal dystrophy 235 gene exome panel sequencing of the entire coding region of genes published by the NHS (2019), converted using PPP (OECD, 2018).

The number of family members accessing genetic testing was estimated by calculating the number of persons with an IRD who reported having one or more family members who had accessed genetic testing. It was then assumed that one of

these family members had accessed this test within the past year.

The unit cost of genetic testing for family members was estimated at €178.46 based on retinal dystrophy 235 gene exome panel testing for known mutations in family members (NHS, 2019d). Utilisation and frequency of service use for family members was based on survey results.

The cost of genetic testing for persons living with an IRD (€963.11) and for family members (€178.46) was applied to the utilisation and frequency of service use, based on country specific survey results, to derive an average cost per person.

The average cost of diagnostic tests for persons living with an IRD and their family members is summarised in Table 6.7.

Table 6.7: Average cost of diagnostic tests (€ 2019)

Service	Cost
Average cost of diagnostic tests per person with an IRD	132
Average cost of diagnostic tests for family members per person with an IRD	142

Source: NHS (2019), OECD (2018), Deloitte Access Economics survey.

6.5 Pharmaceuticals

The cost of pharmaceuticals attributable to IRDs was derived from available literature. Frick et al (2012) estimated health system costs associated with RP based on a cross-sectional retrospective analysis of claims data in the United States. This study found the additional pharmaceutical costs associated with RP in a US population to be $336 per person. This value was converted to RoI terms using health PPP (OECD, 2011) and inflated to 2019 terms using a measure of health inflation in the RoI.

The average cost of pharmaceuticals for persons living with an IRD is summarised in Table 6.8.

Table 6.8: Average cost of pharmaceuticals per person with an IRD (€ 2019)

Product	Cost
Average pharmaceutical costs per person with an IRD	287

Source: Frick et al (2012), OECD (2011), Deloitte Access Economics analysis.

6.5.2 Gene therapy

One gene therapy – Luxturna – has been authorised by the European Medicines Agency (EMA) for the treatment of adult and paediatric patients with vision loss due to inherited retinal dystrophy caused by confirmed biallelic RPE65 mutations and who have sufficient viable retinal cells. At present this product is not reimbursed in the UK or the RoI and as such is not included in this analysis.

6.6 Vitamins and supplements

Country specific survey results were used to estimate the utilisation and out-of-pocket expenditures on vitamins and supplements incurred by persons living with an IRD.

The average cost of vitamins and supplements for persons living with an IRD is summarised in Table 6.9.

Table 6.9: Average cost of vitamins and supplements per person with an IRD (€ 2019)

Product	Cost
Average cost of vitamins and supplements per person with an IRD	65

Source: Deloitte Access Economics analysis.

6.7 Medical research

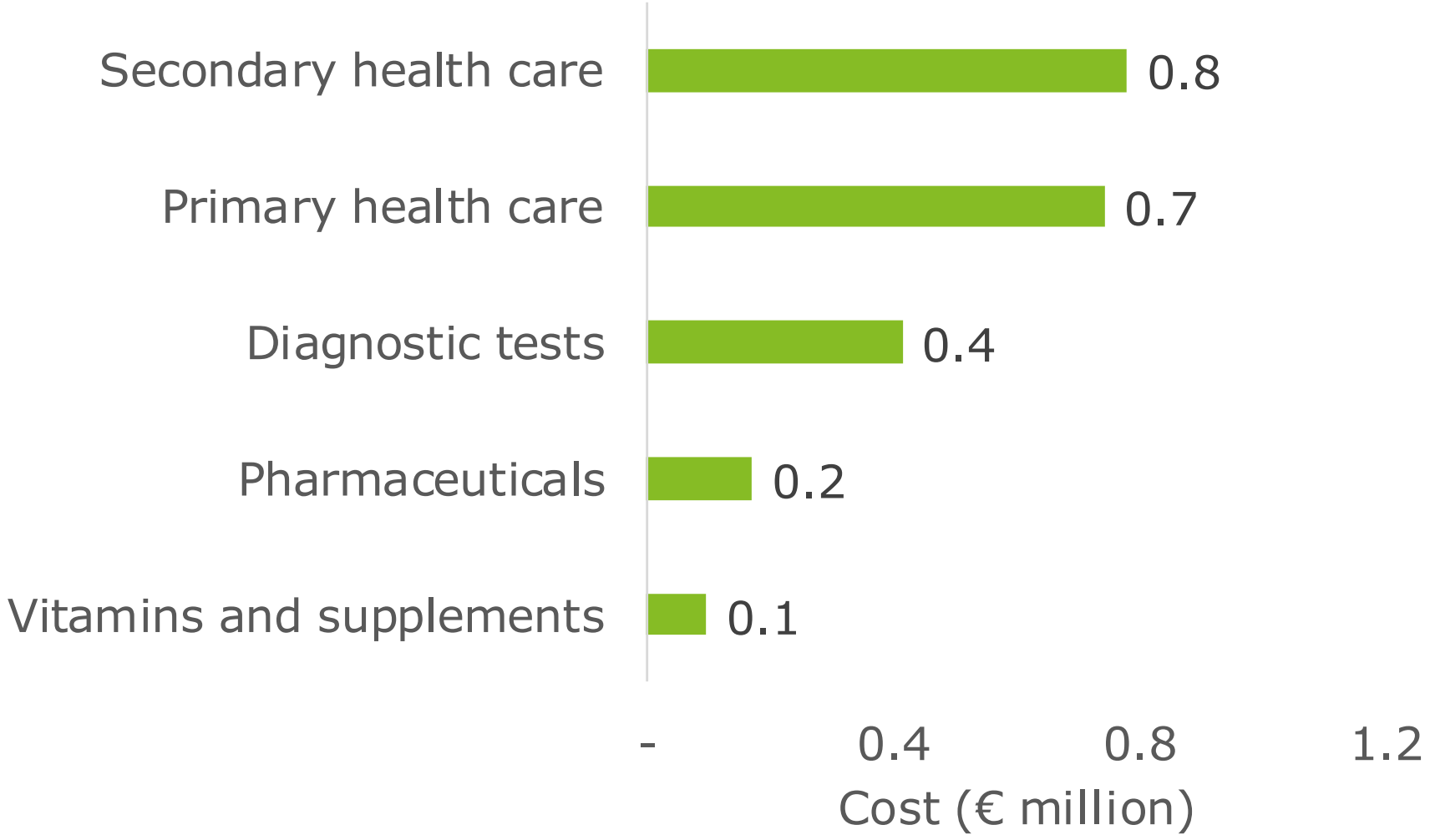
A publically-available database reporting the value of medical research grants offered in RoI was not identified. In the absence of sufficient country specific data, medical research was; therefore, conservatively excluded from the modelled cost

of IRDs in the RoI. A national-level medical research grants database would allow estimation of the average annual value of all grants relating to IRDs that are active in 2019.

6.8 Results

Total health system costs associated with IRDs in the RoI in 2019 were estimated to be €2.2 million. The largest component of health system costs was for secondary health care (€0.8 million), followed primary health care (€0.7 million) and diagnostic tests (€0.4 million). The lowest proportion of the costs were accounted for by pharmaceuticals (€0.2 million), and vitamins and supplements (€0.1 million) (Chart 6.1, Table 6.10).

Chart 6.1: Total health system costs of IRDs (€ million, 2019) in the RoI by cost type



Source: Deloitte Access Economics analysis.

Table 6.10: Total health system costs of IRDs (€ million, 2019) in the RoI by cost type

Cost type	Cost
Secondary health care	0.8
Primary health care	0.7
Diagnostic tests	0.4
Pharmaceuticals	0.2
Vitamins and supplements	0.1
Total	**2.2**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

7 Individual productivity costs

This section describes the approach used to estimate the individual productivity costs – including reduced workforce participation and lost productive time – associated with IRDs in the RoI in 2019.

Key findings

- In 2019, individual productivity costs associated with IRDs in the RoI were estimated to be €9.4 million.
- 74% of individual productivity costs were due to forgone income as a result of reduced workforce participation.
- In the RoI, persons with an IRD were 55.7% less likely to be in paid employment than the general population.
- IRDs resulted in a 9.6% reduction in productivity while at work.

7.1 Summary of approach

Persons living with an IRD can experience reduced capacity to effectively participate in the workforce. Consequently, there are significant productivity costs in terms of reduced workforce participation and lost productive time associated with IRDs.

A human capital approach was used to estimate the productivity costs attributable to IRDs. This involved calculating the difference in employment rate between persons living with an IRD and the general population, multiplied by average weekly earnings (AWE). Similarly, costs incurred through lost productive time were estimated by multiplying the average number of weeks of productive time lost by AWE.

Survey results informing this section were validated through triangulation with literature estimating the productivity costs of IRDs, or conditions with comparable aetiology, in the RoI and internationally.

7.2 Reduced workforce participation

Persons living with an IRD may experience reduced workforce participation relative to the general population due to disadvantages in job-seeking or self-selection out of the labour force. This can lead to significant productivity losses through lost wages.

Most survey participants were not in the workforce[4] (48.1%), followed by those in full-time employment (33.3%) and those employed part-time, casual, or whom were under employed (21.2%) (Table 7.1). Overall, survey participants were employed at a rate of 30.8% compared to the general population employment rate of 69.3% for people aged 15-64 years (CSO, 2019). This translated to an average reduced workforce participation of 55.7% for persons living with an IRD in the RoI.

Costs incurred through reduced workforce participation are estimated by applying the time lost to reduced workforce participation to the RoI general population employment rates and AWE by age and sex.

For comparison, based on 2016 census data, the Central Statistics Office (CSO) (2017) reported that the employment rate for people in the RoI with blindness/VI was 36.4%.

[4] 'Not in the labour force' included participants who indicated they were retired, studying or not employed and not looking for work.

Table 7.1: Distribution of survey participants by employment status in the RoI (n=52)

Employment status	Count (n)	Percentage (%)
Not in the labour force	25	48.1
Employed full-time	16	30.8
Employed part-time, casual, or under employed	11	21.2
Total	**52**	**100.0**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

The following studies estimating the employment rates of persons living with an IRD or condition of a comparable aetiology (i.e. visual impairment) in countries other than the RoI were identified:

- Chaumet-Riffaud et al (2017) surveyed 148 patients, aged 25-50, in France diagnosed with RP between 2013 and 2015. The average employment rate across three levels of visual acuity was 75.3% (see Table 7.2). This was only marginally lowered compared to the employment rate for the entire French population aged 25-49 of 80.2% in 2014.
- Slade and Edwards (2015) noted that adults with a visual impairment were employed 46% less than the general population, who were employed at a rate of 27%. This study was informed by interviews with 1,223 registered blind and partially sighted people in the UK between November 2014 and April 2015.
- Using data from the UK Labour Force Survey (LFS) between October 2012 and July 2015, Hewett and Keil (2016) calculated that the employment rate for the general population in the UK without a disability was 73.8%, approximately 30% higher than those with a self-reported seeing difficulty (45.1%) – see Table 7.2 for the employment rates distributed by age.

- Sherrod et al (2014) used data from 19,849 participants in the 1999-2008 United States (US) National Health and Nutrition Examination Survey to examine the association of vision with work status. The employment rate was estimated to be 42% in participants with a severe visual impairment compared to 69.5% in participants with a normal level of visual function.
- Sander et al (2005) utilised the French national *Handicaps, incapacités, dépendance* (HID) survey to estimate people with severe VI or blindness were employed at a rate of 29%, while those with a mild impairment were employed at a rate of 65%.

The results reported by each identified study are outlined in Table 7.2, Table 7.3 and Table 7.4 These studies were excluded from this analysis in favour of the IRD specific survey results.

Table 7.2: Employment rate (%) UK (2012-2015) by disability status and age

Age	Seeing disability (%)	All people (%)
16-25	25.6	54.0
26-44	47.6	81.2
45-54	56.4	85.9
55-64	46.3	70.1

Source: Hewett and Keil (2016).

Table 7.3: Employment rate for people with RP (%) France (2017) by level of vision

Vision	Percentage of people with the level of vision employed (%)
Low vision	79.5
Mild deficiency	78.8
Blind	67.6
Average	**75.3**

Source: Chaumet-Riffaud et al (2017).

Table 7.4: Summary of evidence on reduced workforce participation due to IRDs or VI/blindness

			Employment		
Study	**Condition**	**Country**	**No VI (%)**	**VI (%)**	**Reduction (% points)**
Chaumet-Riffaud et al (2017)	RP	France	80.2	70.1	10.1
CSO (2017)	VI – General	Ireland	87.1	36.4	50.7
Hewett and Keil (2016)	VI – General	UK	73.8	45.1	28.7
Slade and Edwards (2015)	VI – General	UK	73.0	27.0	46.0
Sherrod et al (2014)	VI – General	US	69.5	42.0	27.5
Sander et al (2005)	VI – General	France	65.0	29.0	36.0

Source: Chaumet-Riffaud et al (2017), CSO (2017), Hewett and Keil (2016), Slade and Edwards (2015), Sherrod et al (2014) and Sander et al (2005).

7.3 Lost productive time

Lost productive time is comprised of presenteeism and absenteeism.

7.3.1 Presenteeism

Presenteeism is the average number of hours per day that an employee loses to reduced performance or impaired function as a result of their condition. This is measurable by a reduction in the quality and efficiency of work produced. Relative to absenteeism, presenteeism may occur more frequently and have a larger effect (Van den Heuvel et al, 2010). Persons living with an IRD may be more likely to report reduced productivity at work as a direct result of their condition. Costs incurred through presenteeism are estimated by applying the time lost to presenteeism to the RoI general population employment rates and AWE by age and sex.

Schakel et al (2018) collected cross-sectional data through interviews and surveys of visually impaired and normally sighted adults in the Netherlands between 2015 and 2016. Using a scale between one and ten, visually impaired and normally sighted respondents placed a value on their level of efficiency while at work. Deloitte Access Economics applied the relative decline in self-reported work efficiency scores – measured on a scale of 1-10 – between the visually impaired (6.6) and normally sighted (7.3) respondents to estimate presenteeism attributable to IRDs of 9.6%.

The estimate, based on the study by Schakel et al (2018), was considered a more robust estimate of IRD-attributable presenteeism than the survey due to the inclusion of a control group. As such, this was selected for inclusion in the analysis.

7.3.2 Absenteeism

Absenteeism is the average number of days per year that an employee is away from work due to their condition.

Absenteeism incurs a productivity cost to:

- **Employers:** Lost output from work absences whilst incurring leave entitlements, management time in processing employee absences, line manager time in rearranging work,

time of back office personnel, and overhead costs of employees such as office space and insurance costs.
- **Government:** Sickness benefit entitlement paid through social insurance.
- **Individuals:** Lost wages due to the gap between paid wages and the sick leave entitlement received from employers and/or government.

The survey results indicate that persons living with an IRD did not take any additional days of leave due to their condition, indicating that IRD-related absenteeism was zero in the RoI.

By comparison, one study estimated that people with sight loss in the US are likely to take an average of 4.1 additional days off work annually by Pezzullo et al (2018). This study was excluded from this analysis in favour of the survey results that are specific to the IRD population.

7.4 Other productivity costs not estimated

Premature mortality results in productivity losses due to forgone potential earnings. This can also result in increased costs associated with employee turnover such as search, hiring and training costs. There is a lack of available data on the risk of premature mortality associated with IRDs. As such, no cost has be allocated to forgone income or search, hiring and training costs due to IRDs in the RoI.

It is noted that the cost of premature mortality associated with VI and/or blindness has been estimated. Wang et al (2001) reported a 70% increased chance of mortality with the presence of any sight loss, accounting for comorbidities. Deloitte Access Economics (2011) previously estimated that the total present value loss from premature mortality and retirement in the RoI was €847,230 in 2010.

7.5 Results

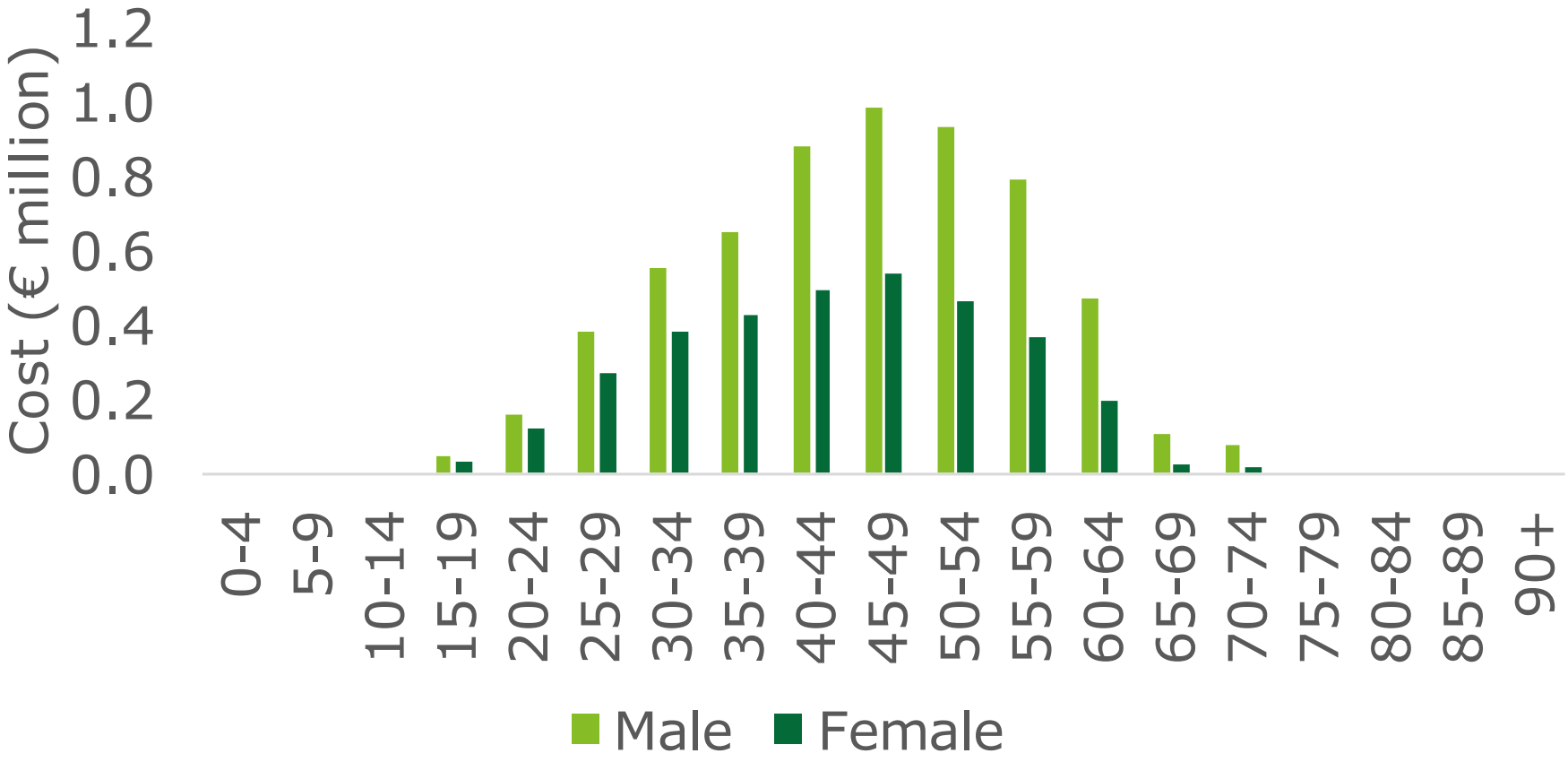
Total productivity costs due to IRDs in the RoI in 2019 were estimated to be €9.4 million. Reduced workforce participation resulted in the greatest proportion of productivity costs at €6.9 million (74%) (Table 7.5). Productivity costs were highest for people aged 45-49 years, reflecting the high earnings and employment rates in that age group (Chart 7.1).

Table 7.5: Total productivity costs of IRDs (€ million, 2019) in the RoI by cost type

Productivity component	Cost
Reduced workforce participation	6.9
Presenteeism	2.4
Absenteeism	-
Total	**9.4**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Chart 7.1: Total productivity costs of IRDs (€ million, 2019) in the RoI by age and sex



Source: Deloitte Access Economics analysis.

8 Other costs

This section describes the approach used to estimate the other costs – including aids and modifications, education, travel, formal and informal care, and deadweight losses of taxation payments – associated with IRDs in the RoI in 2019.

Key findings

- In 2019, other costs attributable to IRDs in the RoI were estimated to be €21.9 million, including formal and informal carer costs of €8.5 million and deadweight losses of €8.2 million.
- Carer costs associated with carers of persons with an IRD include €1.8 million of formal care and €6.7 million of informal care.

8.1 Summary of approach

Other costs attributable to IRDs include aids and modifications, education, travel, formal and informal care, and deadweight losses of taxation payments.

A range of informal care activities may be provided to people with an IRD. Impairment and disability not only affects the individual, but can also affect their family and friends. This can limit the ability of the individual to engage in day-to-day and self-care activities, requiring others to do these activities in their place. People with an IRD and/or their carers may receive welfare payments.

The act of taxation and redistribution creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy, known as deadweight loss. This section calculates the deadweight loss resulting from lost taxation (which must be raised elsewhere) and government expenditure on welfare payments and the health system.

Survey results informing this section were supplemented with data obtained from grey literature (i.e. government publications and research reports). Where possible, these

estimates were validated through triangulation with published literature estimating the other costs of IRDs, or conditions with comparable aetiology, in the RoI and internationally.

8.2 Aid and modifications

Aids and modifications include items such as a guide dog, home modifications, magnifying glasses, Global Positioning System (GPS), electronic mobility devices and other similar products used to assist persons living with an IRD with their daily living.

8.2.1 Utilisation of aids and modifications

The greatest number of survey participants reported using handheld magnifiers (44.7%), followed by screen magnification technology (42.1%), book alternatives (40.8%), a white/long cane (31.6%), high intensity lamps (26.3%), screen reading software (26.3%), magnifying mirrors (21.1%), customised clocks, watches or timers (10.5%), a mini guide or other electronic mobility device (10.5%), large keyboards (6.6%), and portable note takers (6.6%). In the absence of sufficient survey response data, it was conservatively assumed that all persons living with an IRD used a magnifying glass, contrast enhancing filters, green or blue blocking sunglasses, and high vision lamps. Other aids are outlined in Table 8.1.

The number of aids used per annum was also informed based on survey response data. Of people using a specific aid, the largest quantity of aids used per annum was recorded for tactile or large print labels (41.7), followed by book alternatives (19.3), high intensity lamps (2.8), handheld magnifiers (1.4), screen reading software (1.3), and screen magnification technology (1.3). The utilisation of other aids are outlined in Table 8.1.

Table 8.1: Aids and modification used by survey participants in the RoI (n=76)

Aids and modifications	Percentage (%)*	Number used per annum
Contrast enhancing filters	100.0	1.0
Green or blue blocking sunglasses	100.0	1.0
High vision lamps	100.0	1.0
Magnifying glasses	100.0	1.0
Handheld magnifiers	44.7	1.4
Screen magnification technology	42.1	1.3
Book alternatives	40.8	19.3
White cane	31.6	1.0
High intensity lamps	26.3	2.8
Screen reading software	26.3	1.3
Magnifying mirrors	21.1	1.2
Customised clocks, watches or timers	10.5	1.3
Mini guide or other electronic mobility device	10.5	1.0
Large keyboards	6.6	1.2
Portable note takers	6.6	1.0
Guide dog	3.9	1.0
Tactile or large print labels	3.9	41.7

Source: Deloitte Access Economics analysis.
*This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

8.2.2 Costs of aids and modifications

The cost of aids was estimated by applying the average utilisation of aids to their incremental unit cost. Average utilisation was estimated using survey data of the proportion of the IRD population using each aid and the average number of aids used per annum. The cost of each aid was obtained from the out-of-pocket expenditures recorded by the survey, or online shops.

For higher cost items, an annual depreciable amount was used as the basis for estimating an annual cost. This method is used to allocate the cost of assets over their useful life, for example, guide dogs were assumed to have a working life of 8.5 years – meaning that in a given year, it was assumed that, on average, 11.8% of lifetime guide dog costs would be incurred.

The cost of modifications were derived from a study estimating the non-medical costs associated with visual impairment in the UK (Lafuma et al, 2006). No studies estimating the cost of modifications of persons living with an IRD in the RoI were identified. Unit costs were applied to the utilisation obtained from the survey. The cost was converted to RoI terms and then inflated to 2019 terms using a price index published by the CSO (2019) for furniture, household equipment and routine repair of household maintenance. The average cost of modifications associated with IRDs in 2019 was estimated to be €337.16.

The average cost for each aid was collected based on prices reported by online shops. For higher cost items, the total purchase cost was attributed to an annual value using a measure of straight line depreciation. A useful life of five years was assumed for electronic products including large keyboards, screen magnification technology, screen reading software, portable note takers and electronic mobility devices. This assumption was informed by a paper published by Rincon-Aznar et al (2017) commissioned by the Office of National Statistics. An annual depreciable value of guide dogs

was also assumed, based on the working life of 8.5 years reported by a UK Guide Dogs (2019) publication. The annual cost of each item is summarised in Table 8.2.

Table 8.2: Aids and modification unit costs for persons living with an IRD in the RoI (€ 2019)

Aids and modifications	Annual unit cost
Guide dog	6,235
White cane	714
Screen magnification technology	383
Screen reading software	279
Mini guide or other electronic mobility device	263
Portable note takers	240
Green or blue blocking sunglasses	63
High intensity lamps	43
Customised clocks, watches or timers	36
Magnifying glasses	34
High vision lamps	28
Tactile or large print labels	27
Magnifying mirrors	20
Large keyboards	14
Book alternatives	13
Contrast enhancing filters	7
Handheld magnifiers	6

Source: Deloitte Access Economics research.

These unit costs were multiplied by the survey utilisation data to estimate the cost of aids and modifications in the RoI in 2019.

The average aids and modifications costs for persons living with an IRD is summarised in Table 8.3. Overall, expenditure on aids and modifications was estimated to be €2.1 million.

Table 8.3: Average cost of aids and modifications per person (€ 2019)

Product	Cost
Average cost of aids per person	1,019
Average cost of modifications per person	337

Source: Deloitte Access Economics analysis.

8.2.3 Other aids and modifications costs not estimated

Persons living with an IRD may also require aids and modifications for education and employment settings. These products were conservatively excluded from this study to avoid double counting with aids and modifications used in general settings. For example, someone who requires a guide dog for their home use is likely to use the same guide dog, if required, at their place of work.

The survey results indicate that persons living with an IRD pay an average of €65.10 on aids and modifications to assist with work, and €361 on aids and modifications to assist with study. When applied to prevalence estimates, these expenditures total €41,534 of employment-related aids and modifications, and €79.95 of education-related aids and modifications.

8.3 Education

Persons living with an IRD can experience significant barriers to effective learning, thus necessitating specialist support and additional resourcing.

In the RoI, the Department of Education and Skills (DES) provide a number of support mechanisms for the education of children with special education needs (SEN). Students with a disability, such as visual impairment, can receive access to additional teaching support (teachers) and/or special needs assistance (SNA) (National Council for Special Education (NCSE), 2017). Furthermore, students with a sensory deficit can receive support from the Visiting Teacher Service (VTS) – a service that evaluates the needs of students, advises on educational plans and recommend equipment to support students (NCSE, 2019).

By estimating an average cost per student and applying this to the estimated prevalence of students with an IRD, Deloitte Access Economics estimated that the cost of teachers and SNA attributable to IRDs was approximately €340,000. Additionally, by estimating the cost associated with the VTS for visually impaired students and applying it to the estimated prevalence of students with an IRD, Deloitte Access Economics estimated the cost of the VTS due to IRDs was approximately €7,000. This equated to total educational cost attributable to IRDs of €347,000 in 2019.

8.4 Travel

Persons living with an IRD can experience significant barriers to driving a motor vehicle, meaning they must rely on public transport as their primary mode of travel. In the RoI, persons with an IRD may receive access to free public transport.

The survey asked respondents to estimate how much money they had spent on public transport in the previous month for reasons other than health care visits.[5] Respondents were asked to estimate these costs before any refunds, reimbursements or financial support that they may have received.

On average, respondents indicated that they spent €85.73 on public transport in a given month, which was multiplied by 12 to derive the average annual expenditure on public transport

[5] Travel costs for health care visits were included in section 6.

(€1,028.73)[6]. Respondents who indicated that they did not pay anything for public transport, for example due to having a free travel concession card were excluded from the calculation of the average cost. This aims to encapsulate the full cost of public transport to society and not just the out of pocket costs incurred by individuals.

Of all respondents, 53.9% indicated that they used public transport, which was multiplied by the prevalence of IRDs in the RoI, and the average expenditure to estimate the total cost of travel in 2019. The total travel costs for purposes other than health visits were estimated to be €101,000.

These travel costs compare well with a top down approach to estimating travel costs. In 2019, 783,000 persons received free transport through the Free Travel Scheme (FTS) in RoI at a total cost of €95 million (Houses of the Oireachtas, 2019), equating to an average annual per person cost of €102 to the government.

Of those who used the FTS, approximately 160,000 had a disability (Department of Employment Affairs and Social Protection, 2014). The prevalence of IRDs in the RoI as a proportion of people with a disability was applied to this number to estimate that approximately 775 persons living with an IRD used the FTS in 2017-18. This translated to a total cost of €79,000 for subsidised travel attributed to IRDs in the RoI in 2019.

8.5 Formal and informal care

IRDs can result in impairment and disability that not only affects those persons living with the condition, but can also affect their family and friends. Individuals with severe impairment resulting from an IRD can have limited ability to engage in day-to-day and self-care activities, requiring others to do these activities in their place via formal or informal care.

[6] Result cannot be exactly replicated due to rounding of figures in calculation.

8.5.1 Formal care

Formal care can include help from a private nurse or assistance with activities such as childcare, housekeeping and shopping. Formal care may also be referred to as community care, and it may include supported living arrangements (i.e. day care, overnight respite), and other community-based long term care services.

The cost of formal care for persons living with an IRD can be estimated by establishing the:

- Proportion of persons living with an IRD that receive formal care
- Number of hours of formal care each person with an IRD receives
- Cost per hour of formal care for a person with an IRD.

The utilisation and average weekly hours of formal care were estimated using the survey data (see Table 8.4 and Table 8.5). The hourly cost of formal care was calculated based on the annual salary of a home care worker as reported by the Health Service Executive (HSE) (2019) – the government agency responsible for the provision of health and personal social services in the RoI (see Table 8.6).

Table 8.4: Percentage of survey participants who receive formal care in the RoI (n=76)

Formal care received	Count (n)	Percentage (%)
Does not receive formal care	70	92.1
Receives formal care	6	7.9
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Table 8.5: Average weekly hours of formal care received by survey participants receiving formal care in the RoI and UK (n=8)

Service	Hours
Average weekly hours of formal care	14.1

Source: Deloitte Access Economics analysis.

Table 8.6: Hourly cost of formal care (€ 2019) in the RoI

Service	Source	Cost
Hourly cost of formal care	HSE (2019), Baxter and Rabiee (2015)	20.48

Source: Deloitte Access Economics analysis.
Note: Estimated using annual salary plus on-costs. On-costs assumed to be 33%, based on Baxter and Rabiee (2015), and assumed to have 5.6 weeks of leave using annual leave entitlement and sick leave.

These inputs were multiplied together to estimate the cost of community based formal care in the RoI in 2019. Overall, formal care costs were estimated to be €1.8 million.

8.5.1.1 Evidence of the proportion of people receiving formal care – international

The following studies estimating the utilisation of formal care by persons living with an IRD or condition with a comparable aetiology in countries other than the RoI were identified:

- Slade and Edwards (2015) found that 39% of adults with a visual impairment and/or blindness in the UK used a paid support worker. This study was informed by interviews with 1,223 registered blind and partially sighted people between November 2014 and April 2015.
- Ke et al (2007) studied the care use amongst persons aged 50 years and over with age-related macular degeneration (AMD) in Northern Ireland. The average utilisation of formal care was 44.6% across different levels of distance visual

acuity (DVA). The utilisation rates by participants' level of DVA in their better eye are presented in Table 8.7.

- Using data from the Canadian Longitudinal Study on Aging Comprehensive Cohort on the population aged 45-85, Aljied et al (2019) found that 13.3% of people with a visual impairment[7] utilised formal care at home.
- Schmier et al (2006) conducted a survey of 803 patients with AMD in Canada using the Daily Living Tasks Dependent on Vision Questionnaire (DLTV). The average level of formal care usage by all patients was 16.6%. Table 8.8 shows the utilisation of formal care by participants' levels of visual acuity.

These studies were excluded from this analysis in favour of the IRD specific survey results.

Table 8.7: Formal care utilisation (%) Northern Ireland (2007) by DVA

DVA (logMAR)	Percentage of people with the level of DVA utilising formal care (%)
-0.2 – 0.3	34.9
0.4 – 0.9	51.6
1.0 or worse	55.6
Average	**44.6**

Source: Ke et al (2007).

[7] Aljied et al (2019) defined visual impairment as binocular acuity worse than 20/60.

Table 8.8: Formal care utilisation (%) Canada (2006) by visual acuity

Visual acuity	Percentage of people with the level of visual acuity utilising formal care (%)
>3.5	1.5
>3.0 – 3.5	3.9
>2.55 – 3.0	9.6
>2.0 – 2.55	19.0
>1.55 – 2.0	32.4
≤1.5	33.3
Average	**16.6**

Source: Schmier et al (2006).

8.5.1.2 Evidence of the number of hours of formal care received – international

One study estimating the hours of formal care received by persons living with an IRD or condition with a comparable aetiology in a country other than the RoI was found:

- Using data from the Canadian Longitudinal Study on Aging Comprehensive Cohort for the population aged 45-85, Aljied et al (2019) estimated that those who used formal care for a visual impairment did so for an average of 5 hours per week. However, this figure did account for potential comorbidities.

8.5.2 Informal care

A range of informal care activities may be provided to persons living with an IRD. Informal care activities depend on the level of impairment, and can include:

- Collecting relevant prescriptions and organising and timing the administration of medication

- Assistance in daily domestic activities such as cooking and laundry
- Ad-hoc tasks, such as shopping, transport and cleaning activities
- Monitoring of the patient's physical and mental wellbeing.

The opportunity cost method was used to estimate the cost of informal care. This method assumes that time spent providing informal care could be used to engage in paid employment or in leisure activities.

The cost of informal care for persons living with an IRD was estimated by using the:

- Proportion of persons living with an IRD that receive informal care
- Number of hours of informal care each person with an IRD receives
- Hourly cost of providing informal care to a person with an IRD.

The utilisation and average weekly hours of informal care were estimated using the survey data (see Table 8.9 and Table 8.10). The hourly cost of informal care was calculated based on the AWE in the RoI (see Table 8.11).

Table 8.9: Percentage of survey participants who receive informal care in the RoI (n=76)

Informal care received	Count (n)	Percentage (%)
Receives informal care	42	55.3
Does not receive informal care	34	44.7
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Table 8.10: Average weekly hours of informal care received by survey participants receiving informal care in the RoI (n=42)

Service	Hours
Average weekly informal care	16.3

Source: Deloitte Access Economics analysis.

Table 8.11: Hourly cost of informal care (€ 2019) in the RoI

Service	Cost
Hourly cost of informal care	17.5

Source: Deloitte Access Economics analysis.

These inputs were multiplied together to estimate the cost of informal care in the RoI in 2019. Overall, informal care costs were estimated to be €6.7 million.

8.5.2.1 Evidence of the proportion of people receiving informal care – RoI

The following studies estimating the utilisation of informal care by persons living with an IRD or condition with a comparable aetiology in the RoI were found:

- The Irish Health Review Board's (HRB) Annual Report of the National Physical and Sensory Disability Database Committee 2017 showed that 39.0% of the population with a visual deficit utilised informal care (Doyle and Carew, 2017).
- Based on the 2006 National Disability Survey, the CSO (2010) noted that 61.3% of respondents with a visual impairment self-reported requiring some form of informal support from a family member or friend in order to perform daily functions.

IRD specific survey results were favoured over these studies in this analysis.

8.5.2.2 Evidence of the proportion of people receiving informal care – international

The following studies estimating the utilisation of informal care by persons living with an IRD or condition with a comparable aetiology in countries other than the RoI were found:

- Slade and Edwards (2015) found that 48% of adults with a visual impairment and/or blindness in the UK required support from a family member, friend or volunteer. This study was informed by interviews with 1,223 registered blind and partially sighted people between November 2014 and April 2015.
- Ke et al (2007) studied the care use amongst persons aged 50 years and over with AMD in Northern Ireland. The average utilisation of informal care was 60.5% across different levels of DVA. The utilisation rates by participants' level of DVA in their better eye are presented in Table 8.12.
- Using data from the Canadian Longitudinal Study on Aging Comprehensive Cohort for the population aged 45-85, Aljied et al (2019) noted that 15.1% of those with a visual impairment used informal care at home.
- From a study of 546 visually impaired individuals from Portuguese hospitals between 2014 and 2016, it was noted that 39.6% reported using informal care (Marques et al, 2018). Only outpatients with a latest recorded visual acuity of 6/12 or worse in their better seeing eye took part in the study.
- A study of people with visual impairment in Australia showed 61.4% (62) self-reported relying on informal 'home care' to achieve daily functions (Keeffe et al, 2009).
- Schmier et al (2006) conducted a survey of 803 patients with AMD in Canada using the DLTV Questionnaire. The average level of formal care usage by all patients was 41.2%. Table 8.13 shows the utilisation of formal care by participants' levels of visual acuity.
- Based on biennially collected panel data from 1993 to 1994 in the USA on people aged 70 and over, Shih and Lustig (2002) found that 64.2% of those with a visual impairment relied on the use of an informal caregiver.

These studies were excluded from this analysis in favour of the IRD specific survey results.

Table 8.12: Informal care utilisation (%) Northern Ireland (2007) by DVA

DVA (logMAR)	Percentage of people utilising informal care (%)
>0.3	37.3
0.4 – 0.9	69.9
1.0≤	88.9
Average	**60.5**

Source: Ke et al (2007).

Table 8.13: Informal care utilisation (%) Canada (2006) by visual acuity

Visual acuity	Percentage of people with the level of visual acuity utilising care (%)
>3.5	3.3
>3.0 – 3.5	21.0
>2.55 – 3.0	39.5
>2.0 – 2.55	68.1
>1.55 – 2.0	62.2
≤1.5	53.3
Average	**41.2**

Source: Schmier et al (2006).

8.5.2.3 Evidence of the number of hours of informal care received – RoI

One study estimating the utilisation of formal care by persons living with an IRD or condition with a comparable aetiology in the RoI was found:

- Green et al's (2016) study on the cost of blindness in RoI used data from the government data to estimate that blind people utilise an average of 14.7 hours of informal care per week as shown in Table 8.14.

Table 8.14: Informal care utilisation by blind people (hours) Ireland (2016)

Hours provided (week)	Hours received	Percentage (%) of blind persons receiving care
1-14 hours	1.0	58.0
15-28 hours	15.0	11.0
29-42 hours	29.0	6.0
43+ hours	43.0	25.0
Average	**14.7**	**100.0**

Source: Green et al (2016).

8.5.2.4 Evidence of the number of hours of informal care received – international

The following studies estimating the utilisation of informal care by persons living with an IRD or condition with a comparable aetiology in countries other than the RoI were found:

- Using data from the Canadian Longitudinal Study on Aging Comprehensive Cohort (for people aged 45-85), Aljied et al (2019) found that people with a visual impairment used informal care at home for an average of 8.3 hours per week.
- Khan et al (2016) undertook a study of the burden among caregivers of people with a visual impairment in Canada. Of the 236 participants (32% legally blind; 68% low vision),

carers reported providing a daily average of 2.2 hours of close supervision, or 15.4 hours per week.
- Weyer-Wendl and Walter (2016) surveyed 150 informal carers of patient with wet age-related macular degeneration (wAMD) in Germany. The average amount of care provided was 6.4 hours per week as shown in Table 8.15.
- A study of people with VI in Australia revealed that the 101 participants required an estimated combined total of 15,369 hours of informal care[8] during one year. This translated to 2.93 hours of informal care per person, per week (Keeffe et al, 2009).

Table 8.15: Informal care utilisation by people with wAMD (hours) Germany (2016) by visual acuity

Visual acuity	Hours
>0.3	4.3
≤0.3 - >0.1	5.6
≤0.1	11.9
All	**6.4**

Source: Weyer-Wendl and Walter (2016).

8.6 Residential care

Persons living with an IRD can experience severe impairment or disability requiring continuous care and supervision. Such persons may require long term care in the form of a residential care service (Wang et al, 2003). Residential care includes the independent sector residential care, local authority residential care and nursing care.

Persons living with an IRD who are unable to live at home may be entitled to residential services provided by voluntary organisations funded by the HSE. Individuals may be required

[8] This study included the following as types of informal care: health care, home help, personal affairs, personal care, communication, transportation, social activities, and other.

to make means tested contributions. Community care services are usually provided by the HSE or by voluntary organisations in conjunction with, or on behalf of, the HSE.

Due to a lack of available country specific data, residential care costs attributable to IRDs in the RoI were estimated by applying the proportion of persons with an IRD who use such care in the UK (1.06%)[9] to the prevalence of IRDs in the RoI, multiplied by the average weekly cost of providing residential and community care (€1,535.5)[10]. Deloitte Access Economics estimated that the cost of residential care in the RoI due to IRDs was €1.3 million (Table 8.16).

Table 8.16: Total expenditure on long term care for IRDs (€ million 2019)

Payer	Percentage (%)	Total cost
Individuals	56.4	0.7
Government	43.6	0.6
Total	**-**	**1.3**

Source: NHS Digital (2016) and Deloitte Access Economics analysis.

8.7 Deadweight losses of taxation payments

This section calculates the deadweight losses arising from raising and administering taxation (i.e. transfer) payments, including government and social insurance expenditure on health and welfare.

While transfer payments alone do not impose a net cost to society, the act of raising and redistributing tax distorts the

[9] Deloitte Access Economics estimated that 1.06% of persons living with an IRD in the UK utilise residential and/or community care.

[10] The HSE (2019) indicated that the weekly cost of providing residential and community services ranged from €889 – €2,182. The average of this range was applied.

natural pricing mechanisms in the economy leading to inefficient resource allocation. Taxes alter the price and quantity of goods sold compared to what they would be if the market were not distorted. In a practical sense, this distortion reveals itself as a loss of efficiency in the economy, which means that raising €100 of taxation revenue requires consumers and producers to give up more than €100 of value. This, in turn, creates a reduction in consumer and producer surplus by diminishing the value of trade between these parties that would otherwise be achieved – a deadweight loss. As such, deadweight losses represent a real net cost to the economy.

8.7.1 Welfare payments

The cost of welfare payments themselves are not included in the cost of IRDs. However, the deadweight losses arising from raising and administering welfare payments are included in the total cost of IRDs.

Persons living with an IRD may be eligible for several forms of government support:

- Blind Pension
- Blind Person's Tax Credit
- Blind Welfare Allowance
- Disability Allowance
- Domiciliary Care Allowance (DCA)
- Illness Benefit
- Invalidity Pension
- Jobseeker's Benefit
- Living Alone Increase (LAI).

Additionally, informal carers of a person or persons living with an IRD may be eligible for the:

- Carer's Allowance
- Carer's Benefit
- Carer's Support Grant
- Child Benefit.

A description of each of these welfare payments is provided in 0.

Welfare payments were estimated by applying the average utilisation of welfare payments to the weekly entitlement

associated with each payment. Average utilisation was estimated using country specific survey data of the proportion of respondents who received each payment. The weekly entitlement amount for each welfare payment was calculated based on the weighted average amount received by all recipients of that welfare type[11].

The majority of participants from the RoI (68.4%) reported receiving support from their government (Table 8.17 and Table 8.18).

Table 8.17: Government welfare payment utilisation of survey participants in the RoI (n=76)

Government support utilisation	Count (n)	Percentage (%)
Supported	52	68.4
Unsupported	24	31.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

[11] Individuals receive different amounts for the same welfare type depending on their level of need.

Table 8.18: Summary of welfare received by persons living with an IRD (€ 2019) by welfare type

Welfare type	Welfare	Weekly entitlement
Individual	Illness Benefit	229.1
	Invalidity Pension	226.3
	Disability Allowance	220.1
	Blind Pension	217.2
	Jobseeker's Benefit	216.8
	Blind Welfare Allowance	60.0
	Blind Person's Tax Credit	31.7*
	LAI	9.0
Carer	Carer's Allowance	245.5
	Carer's Benefit	226.1
	Carer's Support Grant	32.7
	DCA	77.4

Source: Citizens Information Board (2019).
*This reflects a tax credit as opposed to a direct payment.

These average welfare payments were applied to data on individual payment types to estimate the total cost of welfare payments to persons living with an IRD, which was €11.4 million in 2019. In addition, the total cost of welfare payments to carers of persons living with an IRD was estimated to be €4.8 million in 2019. Therefore, the total

welfare payments due to IRDs were estimated to be €16.3 million in 2019.

8.7.2 Reduced taxation revenue

Lower employment participation and lower output (e.g. due to absenteeism or presenteeism) reduce the possible taxation revenue government can collect. The reduction in taxation revenue was estimated by applying an average personal income or company tax rate – which were assumed to be 25.4% and 25.0%, respectively – to lost individual or company earnings.

The total reduction in taxation revenue was estimated to be €4.1 million in 2019.

8.7.3 Deadweight loss of taxation payments and administration

The deadweight loss due to lost taxation revenue (given an assumption of no change in spending) or additional expenditure on government programs (e.g. health or welfare) can be estimated by applying the marginal burden of taxation to the total of lost taxation and government expenditures.

The Department of Public Expenditure and Reform (DPER) (2019) estimated the shadow price of public funds (SPPF)[12] to be 1.30 (where 1 represents zero SPPF). Consequently for every additional €1 raised by the RoI Government to fund costs associated with IRDs a €0.30 burden, or efficiency loss, was applied.

The total deadweight loss due to IRDs were estimated to be €7.9 million in 2019, as shown in Table 8.19.

[12] Rather than the marginal cost of public funds (MCPF) which is utilised by many countries such as in the UK, the RoI utilises the SPPF which encompasses both the MCPF and the average cost of taxation (the welfare cost of yielding current revenues, given existing tax structures) (O'Callaghan and Prior, 2018)

Table 8.19: Deadweight losses (€ million 2019) due to IRDs

Cost type	Total cost	Resulting deadweight loss
Welfare payments	16.3	4.9
Government programs (e.g. health)	5.9	1.8
Lost individual taxes	1.8	0.5
Lost carer taxes	1.7	0.5
Lost company taxes	0.6	0.2
Total	**26.3**	**7.9**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

8.8 Results

Total other costs due to IRDs in the RoI in 2019 were estimated to be €21.9 million. Deadweight losses resulted in the greatest proportion of other costs at €8.2 million (37%) (Table 8.19), followed by informal care (€6.7 million, 31%), formal care (€1.8 million, 8%) and residential care (€1.3 million, 6%). See Chart 8.1 for the distribution of costs by age and sex, and Chart 8.2 for the distribution by payer.

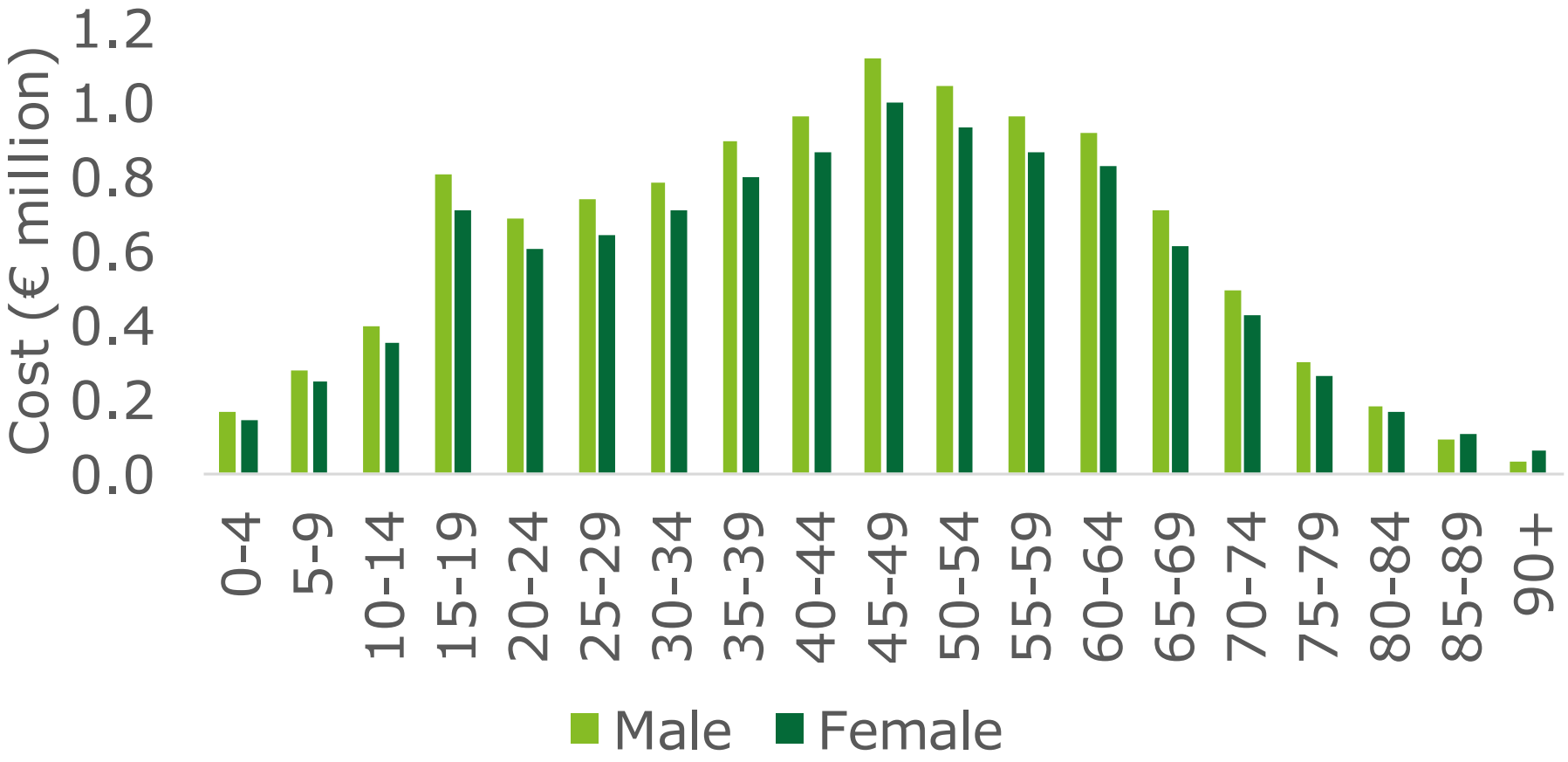
The largest component of this cost is borne by society (37%), with families and government incurring 24% each, and individuals taking on 15% of the costs. Other costs by payer are summarised in Chart 8.2.

Table 8.20: Total other costs of IRDs (€, 2019) in the RoI by cost type

Cost type	Cost per person (€)	Cost (€ million)
Deadweight losses	5,383	8.2
Informal care	4,423	6.7
Aids and modifications	1,861	2.8
Formal care	1,185	1.8
Residential care	855	1.3
Travel	474	0.7
Education	228	0.3
Total	**-**	**21.9**

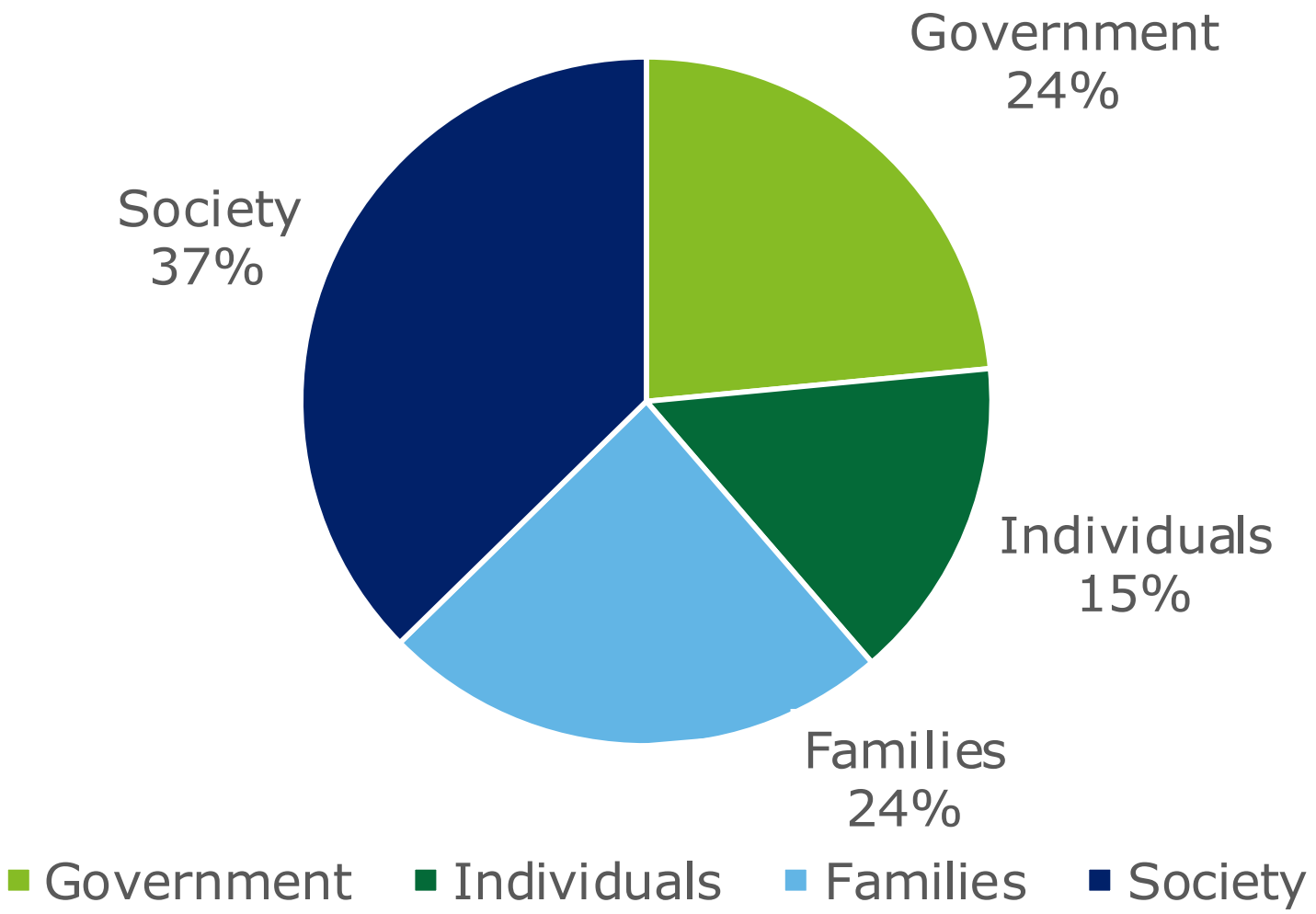
Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Chart 8.1: Total other costs of IRDs (€ million, 2019) in the RoI by age and sex



Source: Deloitte Access Economics analysis.

Chart 8.2: Proportion (%) of total other costs of IRDs in the RoI (2019) by payer



Source: Deloitte Access Economics analysis.

9 Wellbeing costs

This section describes the approach used to estimate wellbeing costs associated with IRDs in the RoI in 2019.

Key findings

- In 2019, persons living an IRD in the RoI were estimated to experience a total of 234 disability adjusted life years (DALYs).
- Total wellbeing costs associated with IRD in 2019 were estimated to be €10,492 per person and €16.0 million in total.

9.1 Summary of approach

Wellbeing costs were estimated using the World Health Organization (WHO) burden of disease methodology. This is a non-financial approach, where pain, suffering and premature mortality are measured in terms of DALYs.

DALYs are composed of premature mortality (years of life lost due to premature death – YLL) and morbidity (years of healthy life lost due to disability – YLD) components. DALYs are calculated by assigning disability weights to various health states, where zero represents a year of perfect health and one represents death. Other health states are given a weight between zero and one to reflect the quality of life that is lost due to a particular condition. For example, a disability weight of 0.2 is interpreted as a 20% loss in the quality of life relative to perfect health for the duration of the condition.

Disability weights were obtained from the IHME's *Global Burden of Disease Study 2017* and are classed into three levels of severity (see 0). Disability weights were applied to the prevalence of IRDs in the RoI and discounted at a rate of 3% consistent with WHO methodology (WHO, n.d.).

Table 9.1: Disability weights per person due to 'other vision loss' (2017)

Sequela	Health state (severity of vI)	Health state description	Disability weight
Moderate vision impairment due to other vision loss	Distance vision, moderate impairment	Vision problems that make it difficult to recognize faces or objects across a room	0.031
Severe vision impairment due to other vision loss	Distance vision, severe impairment	Severe vision loss, which causes difficulty in daily activities, some emotional impact, and some difficulty going outside the home without assistance	0.184
Blindness due to other vision loss	Distance vision blindness	Completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance	0.187

Source: IHME (2018).

For the purposes of this report, a single disability weight of 0.153 was applied to DALYs. This reflects an average of the three disability weights by severity, weighted by the estimated distribution across the three levels of severity.[13]

DALYs were converted into euros using an estimate of the value of a statistical life year (VSLY). The VSLY is an estimate of the value society places on an anonymous life. Due to an absence of data, Deloitte Access Economics estimated the VSLY for the RoI by converting the UK VSLY[14] into euros using PPP. The estimated value was €67,984 per person at April 2018 and was inflated using the RoI Health Consumer Price Index (CPI) to reflect the VSLY as at April 2019 (see Table 9.2)

Table 9.2: RoI VSLY (€)

Country	Date	VSLY
UK	April 2018	£60,000
RoI	April 2018	€67,984
RoI	April 2019	€68,388

Source: HM Treasury (2018), CSO (2019), OECD (2019) and Deloitte Access Economics calculations.

These estimates are supported by the survey results wherein the vast majority of participants reported experiencing negative impacts on their wellbeing as a result of their IRD, with 86.6% reporting experiencing anxiety, 67.1% depression, 50.0% social isolation, 45.1% financial stress and 14.6% 'other'

[13] The distribution of prevalent IRD cases in the RoI by severity was estimated based on the average of studies by Bunce (2006), Bunce (2010) and Quartilho (2016), using vision loss certifications in the UK (NHS, 2017).

[14] The VSLY in the UK was derived from *The Green Book,* a report published by HM Treasury, which is the 'central government guidance on appraisal and evaluation' in the UK (HM Treasury, 2018).

wellbeing effects (Table 9.3). The 'other' category included negative impacts on persons living with an IRD's wellbeing due to fear, stress, fatigue, hopelessness, loneliness, panic attacks, suicidal thoughts and the development of tics.

Table 9.3: Wellbeing status of survey participants (persons living with an IRD) in the RoI (n=76)

Wellbeing (persons living with an IRD)	Percentage (%)*
Anxiety	85.5
Depression	63.2
Social isolation	44.7
Financial stress	43.4
Other	7.9

Source: Deloitte Access Economics analysis.
*This question allowed for the selection of multiple answers, hence, the percentages did not sum to 100.

Furthermore, the wellbeing effects of IRDs are not limited to persons living with an IRD. 51.2% of survey participants reported that close family members had experienced feelings of depression, anxiety, or another mental health condition as a result of their IRD. The parents of children (under 18) living with an IRD reported feelings of anxiety (17.1%), depression (13.4%), and 'other' mental health impacts (3.7%) (Table 9.4). The 'other' category included negative impacts on the parents of children (under 18) living with an IRD's wellbeing due to stress, loneliness and concerns for the safety of their child.

In addition, the majority of persons living with an IRD (73.2%) and the parents of children (under 18) living with an IRD (75%) were frustrated by the lack of awareness and support for IRDs (Table 9.5).

Table 9.4: Wellbeing status of survey participants (the parents of children (under 18) living with an IRD) in the RoI (n=24)

Wellbeing (the parents of children under 18 living with an IRD)	Percentage (%)*
Anxiety	75.0
Depression	50.0
Other mental health impacts	8.3

Source: Deloitte Access Economics analysis.
*This question allowed for the selection of multiple answers, hence, the percentages did not sum to 100.

Table 9.5: Degree of survey participant frustration with the lack of awareness and support for IRDs in the RoI and UK (n=76)

	Percentage (%)				
Participant type	**Strongly disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
Persons living with an IRD	1.9	0.0	1.9	7.5	5.7
The parents of children (under 18) living with an IRD	7.5	1.9	17.0	30.2	26.4

Source: Deloitte Access Economics analysis.

9.2 Results

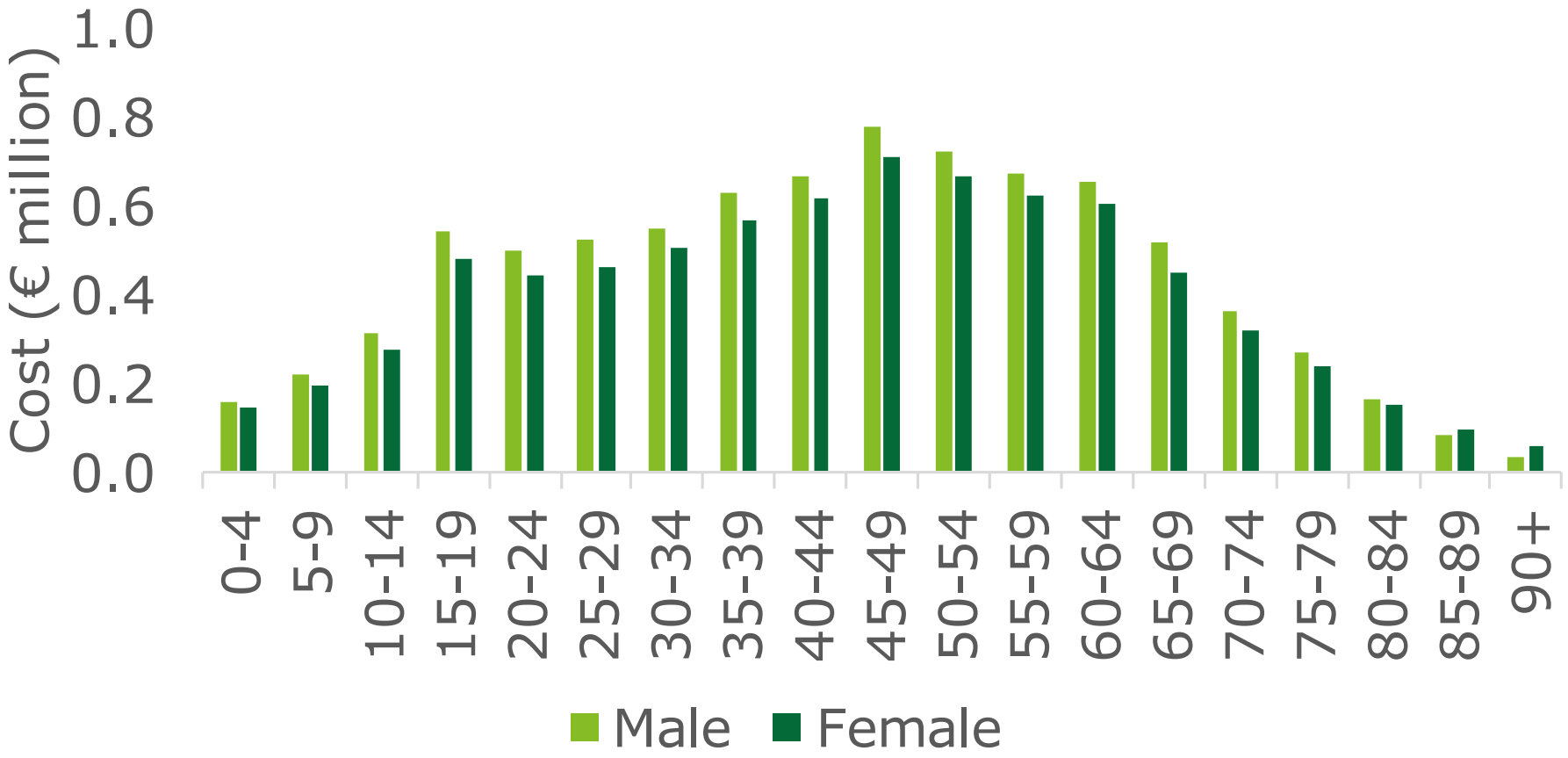
In 2019, persons living with an IRD in the RoI were estimated to experience 234 DALYs overall. This equated to total wellbeing costs of €16.0 million or €10,492 per person (see Table 9.6). Wellbeing costs by age and sex are displayed in Chart 9.1.

Table 9.6: Total DALYs and wellbeing costs of IRDs (2019) in the RoI

Parameter	Per person	Total
DALYs		234
Wellbeing costs	**€10,492**	**€16.0 million**

Source: Deloitte Access Economics analysis based on IHME (2016), HM Treasury (2018).

Chart 9.1: Total wellbeing costs of IRDs (€ million, 2019) in the RoI by age and sex



Source: Deloitte Access Economics analysis based on IHME (2016), HM Treasury (2018).

10 Sensitivity analysis

In many cases, the inputs underlying a cost-of-illness analysis are uncertain and changes in these inputs may have a significant impact upon the total estimate of the costs of IRDs in the RoI in 2019. Given the limited published data on the prevalence of IRDs in the RoI, sensitivity analysis using an upper bound sensitivity estimate based on the highest published prevalence estimate available was undertaken.

The overall upper bound prevalence rate was based on Orphanet (2019), which reports estimated prevalence for a range of rare diseases, including IRDs. While this source reports that its underlying research is based on a systematic review of PubMed, grey literature, and expert consultation (Orphanet, 2019), primary data informing these estimates is difficult to ascertain and verify, and therefore does not inform the base estimates.

Using this approach, an upper bound prevalence rate of 0.0525% was estimated for the RoI – 68.8% higher than the base prevalence estimate of 0.0311% reported in this analysis.

The upper bound prevalence rate of RP is in line with that reported by O'Neill et al (2007), who estimated the prevalence of RP in Northern Ireland. However, this study was excluded from further analysis since the full text could not be located. Similarly, Stone (2007) conducted a study which examined the prevalence of LCA in the United States. This study was also excluded from analysis in favour of European-specific prevalence results provided by Bertelsen et al (2014).

Table 10.1 and Table 10.2, below, outline the base case and upper bound prevalence estimates for each IRD included in this study.

Table 10.1: Prevalence of IRDs (2019) in the RoI by condition (base case and upper bound)

	Base case			Upper bound		
IRD	**Rate (%)**	**Cases**	**Proportion (%)**	**Rate (%)**	**Cases**	**Proportion (%)**
RP	0.0154	755	49.6	0.0261	1,274	49.60
Usher syndrome	0.0039	189	12.4	0.0065	320	12.44
Stargardt	0.0032	154	10.1	0.0053	260	10.13
LCA/EOSRD	0.0024	116	7.6	0.0040	196	7.63
Best disease	0.0015	73	4.8	0.0025	124	4.82
Cone dystrophy	0.0013	64	4.2	0.0022	108	4.21
Cone-rod dystrophy	0.0012	59	3.9	0.0020	100	3.90
Achromatopsia	0.0011	54	3.5	0.0018	90	3.52
XLRS	0.0007	35	2.3	0.0012	60	2.32
Choroideremia	0.0004	22	1.4	0.0008	37	1.43
Total IRDs	**0.0311**	**1,522**	**100.0**	**0.0525**	**2,569**	**100.00**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Table 10.2: Prevalence of IRDs (2019) in the RoI by age and sex (upper bound)

	Male		Female		Total	
Age group	**Rate (%)**	**Cases**	**Rate (%)**	**Cases**	**Rate (%)**	**Cases**
0-9	0.0179	61	0.0167	54	0.0173	114
10-19	0.0409	138	0.0377	121	0.0394	259
20-29	0.0554	165	0.0494	146	0.0524	311
30-39	0.0551	189	0.0473	173	0.0511	362
40-49	0.0649	232	0.0586	214	0.0617	446
50-59	0.0758	224	0.0689	207	0.0723	432
60-69	0.0810	189	0.0712	170	0.0761	359
70-79	0.0675	102	0.0555	90	0.0613	192
80+	0.0678	45	0.0497	49	0.0571	94
Total	**0.0556**	**1,346**	**0.0495**	**1,223**	**0.0525**	**2,569**

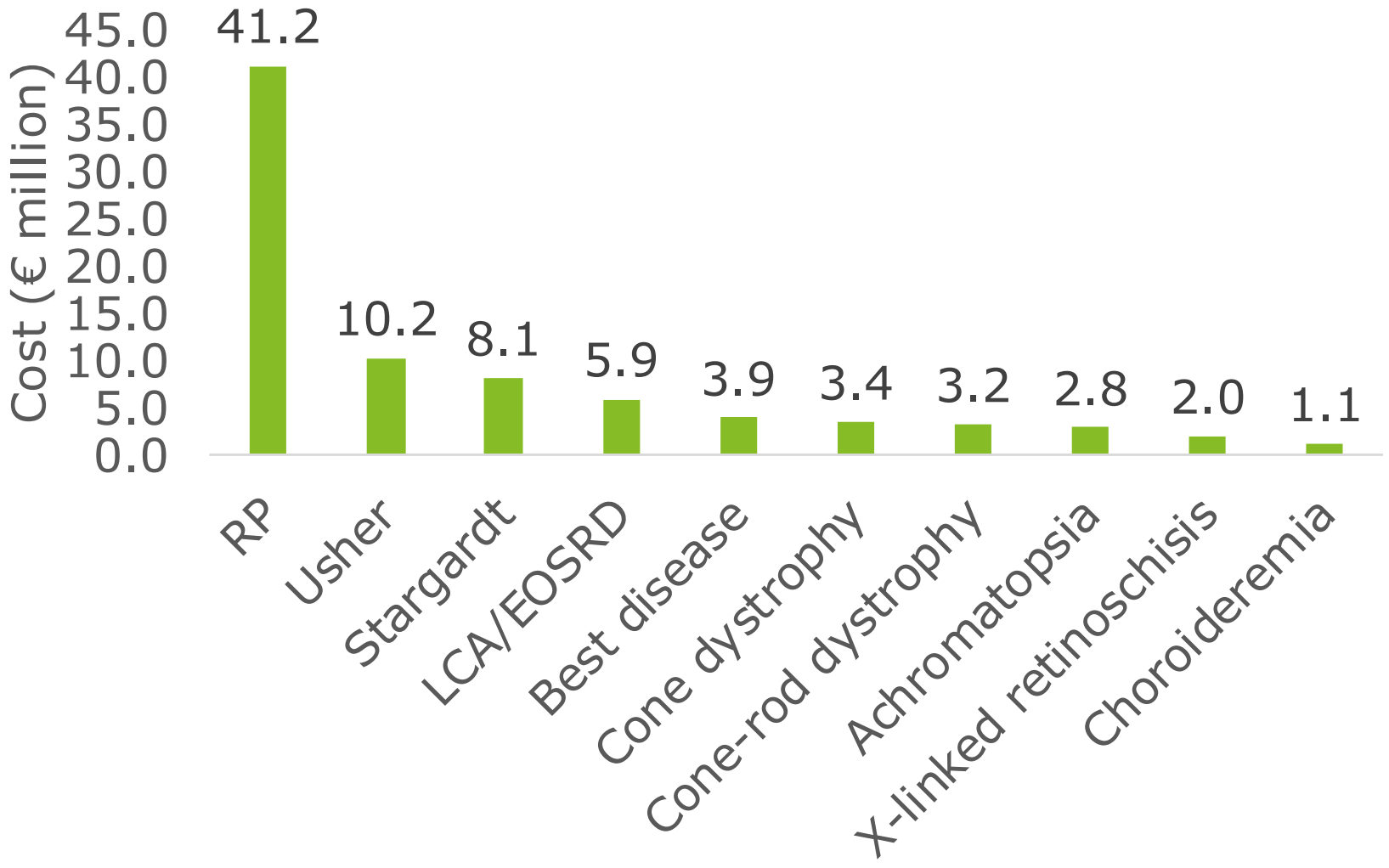
Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

10.1 Results

The upper bound sensitivity scenario yielded an overall estimate of the cost of IRDs in RoI of €81.7 million. The variance between upper and lower bound costs by condition are shown in 0, while Table 10.3 shows the upper and lower bound costs by condition.

The most sensitive components of cost included the wellbeing cost, followed by productivity costs (Chart 10.2). Table 10.4 shows the upper bound and base case costs, by component.

Chart 10.1: Sensitivity analysis results (€ million, 2019) in the RoI by condition



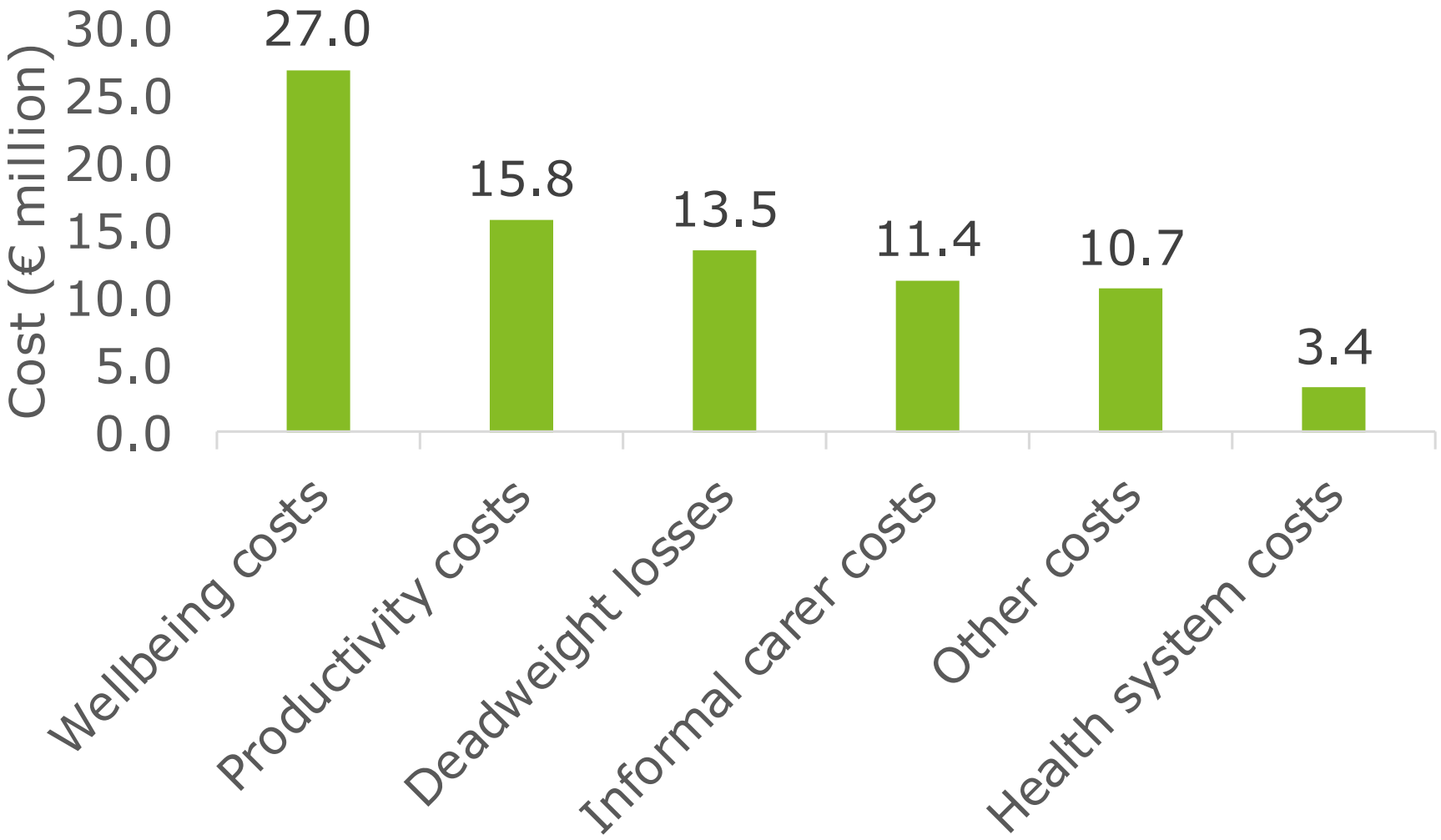
Source: Deloitte Access Economics analysis.

Table 10.3: Sensitivity analysis results (€ million, 2019) in the RoI by condition

IRD	Base case	Upper bound
RP	24.9	41.2
Usher	6.2	10.2
Stargardt	4.9	8.1
LCA/EOSRD	3.6	5.9
Best disease	2.3	3.9
Cone dystrophy	2.1	3.4
Cone-rod dystrophy	1.9	3.2
Achromatopsia	1.7	2.8
X-linked retinoschisis	1.2	2.0
Choroideremia	0.7	1.1
Total	**49.5**	**81.7**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Chart 10.2: Sensitivity analysis results (€ million, 2019) in the RoI by cost type



Source: Deloitte Access Economics analysis.

Table 10.4: Sensitivity analysis results (€ million, 2019) in the RoI by cost type

Cost type	Base case	Upper bound
Wellbeing costs	16.0	27.0
Productivity costs	9.4	15.8
Deadweight losses	8.2	13.5
Informal carer costs	7.0	11.4
Other costs	6.7	10.7
Health system costs	2.2	3.4
Total costs	**49.5**	**81.7**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

11 Conclusion

11.1 Summary of total costs

This analysis found that IRDs imposed significant economic and wellbeing costs on the RoI population in 2019. As it currently stands, persons living with an IRD incur significant economic costs and reductions in their quality of life. In addition to the costs incurred by these persons, their families, friends, government, employers and society all incur significant economic costs due to IRDs.

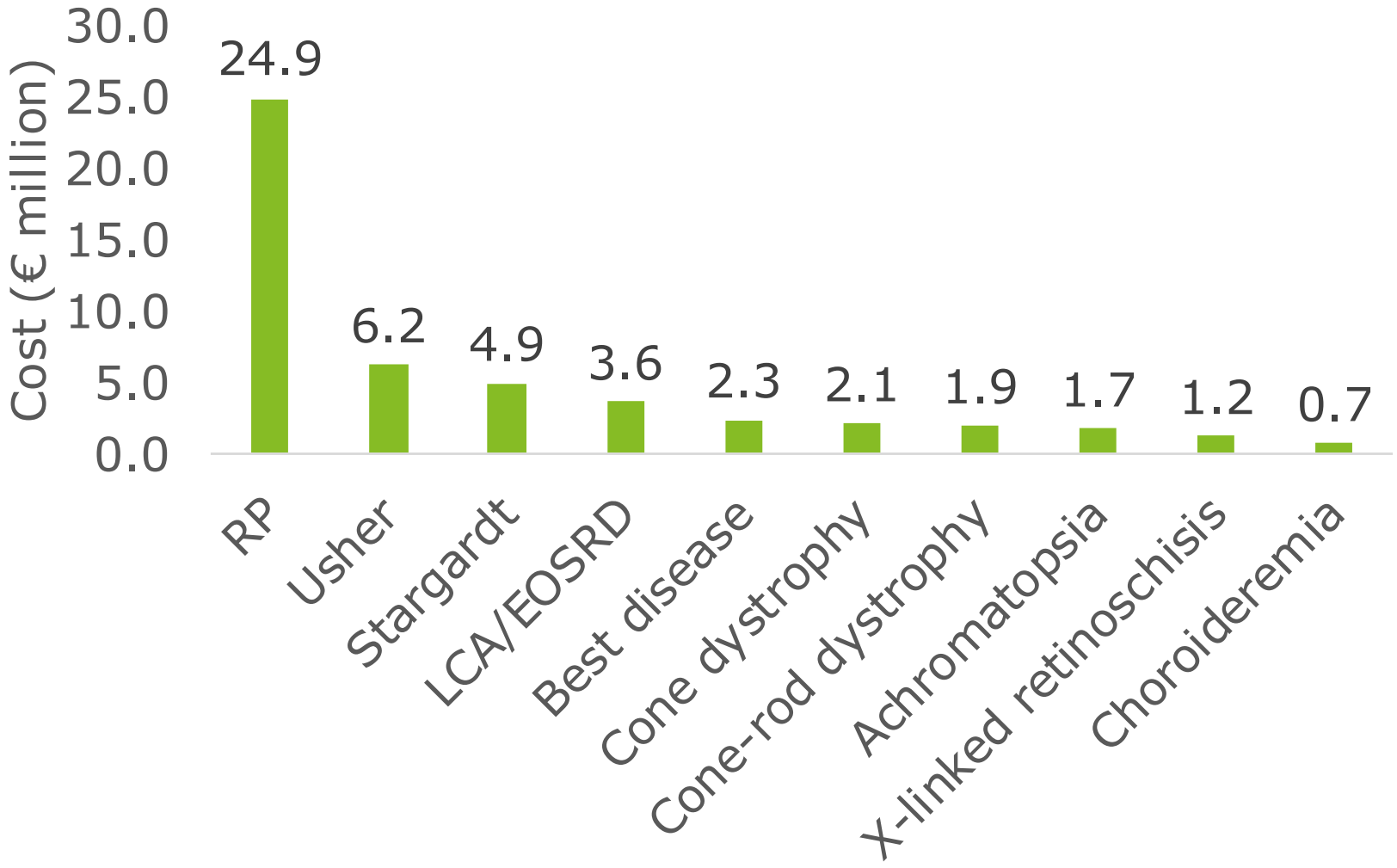
Total costs attributable to IRDs in the RoI were estimated to be €49.5 million in 2019, comprising both economic (€33.5 million) and wellbeing costs (€16.0 million) (Chart 11.1 and Table 11.1).

Of the ten IRDs within scope, RP incurred the greatest proportion of total costs at €24.9 million (50.3%), followed by Usher syndrome (€6.2 million, 12.5%), Stargardt disease (€4.9 million, 9.9%), LCA/EOSRD (€3.6 million, 7.2%), Best disease (€2.3 million, 4.7%), cone dystrophy (€2.1 million, 4.2%), cone-rod dystrophy (€1.9 million, 3.9%), achromatopsia (€1.7 million, 3.4%), XLRS (€1.2 million, 2.4%) and choroideremia (€0.7 million, 1.4%) (Chart 11.2 and Table 11.2).

Wellbeing costs comprised the largest share of total costs at €16.0 million (32.3%), followed by productivity costs (€9.4 million, 18.9%), deadweight losses (€8.2 million, 16.6%) other costs (€7.0 million, 14.2%) and informal carer costs (€6.7 million, 13.6%) (Chart 11.2 and Table 11.2). This means that in addition to imposing significant economic costs, IRDs result in pain and suffering that leads to a significant wellbeing impact for persons living with an IRD.

Individuals the largest share of total costs at 51%, followed society/other (17%), family/friends (16%), government (12%) and employers (4%) (Chart 11.3).

Chart 11.1: Total economic costs of IRDs (€ million, 2019) in the RoI by condition



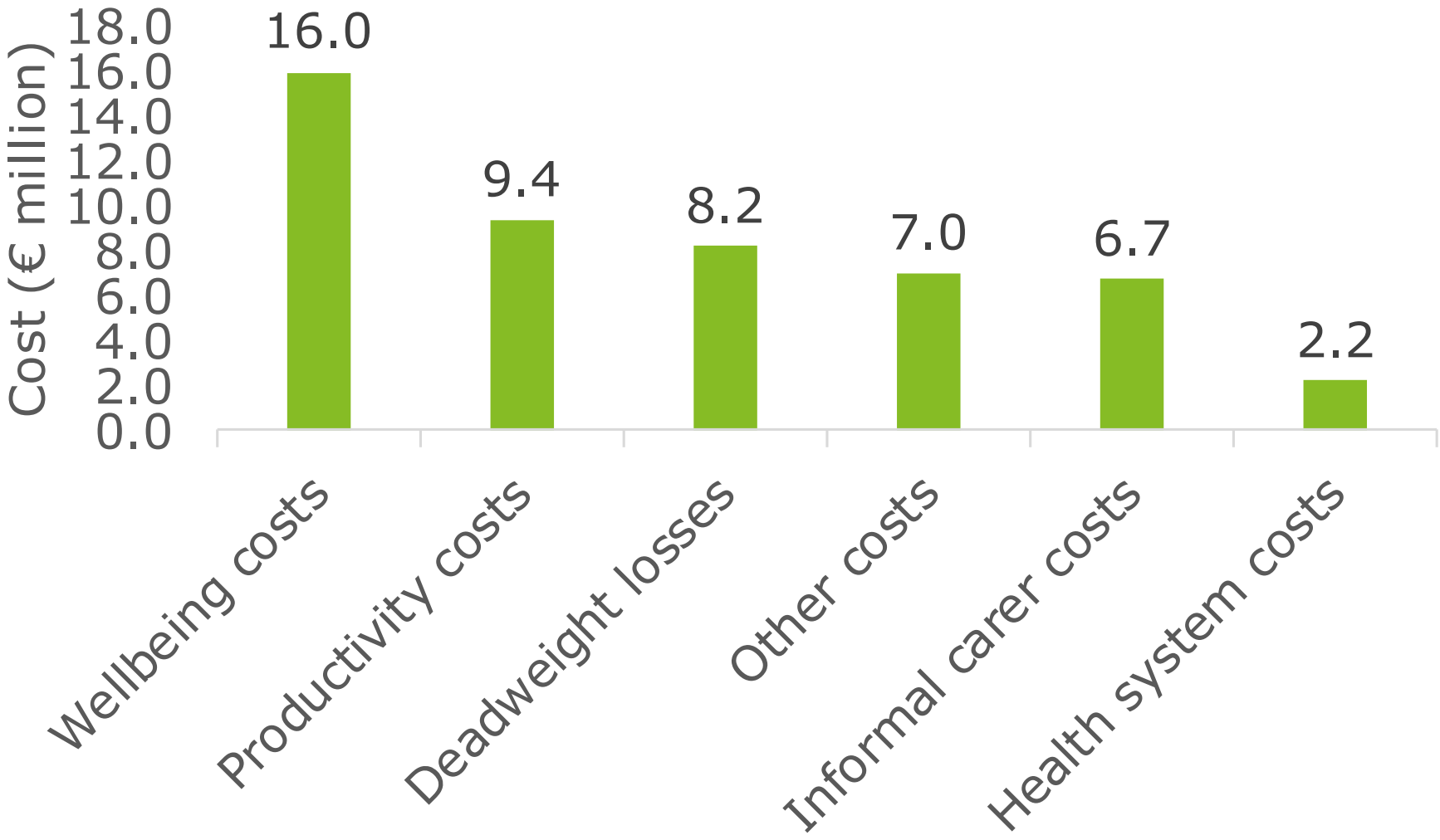
Source: Deloitte Access Economics analysis.

Table 11.1 Total costs of IRDs (€ million, 2019) in the RoI by condition

IRD	Percentage of total cost (%)	Cost
RP	50.3	24.9
Usher syndrome	12.5	6.2
Stargardt disease	9.9	4.9
LCA/EOSRD	7.2	3.6
Best disease	4.7	2.3
Cone dystrophy	4.2	2.1
Cone-rod dystrophy	3.9	1.9
Achromatopsia	3.4	1.7
XLRS	2.4	1.2
Choroideremia	1.4	0.7
Total IRDs	**100.0**	**49.5**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Chart 11.2: Total costs of IRDs (€ million, 2019) in the RoI by cost type



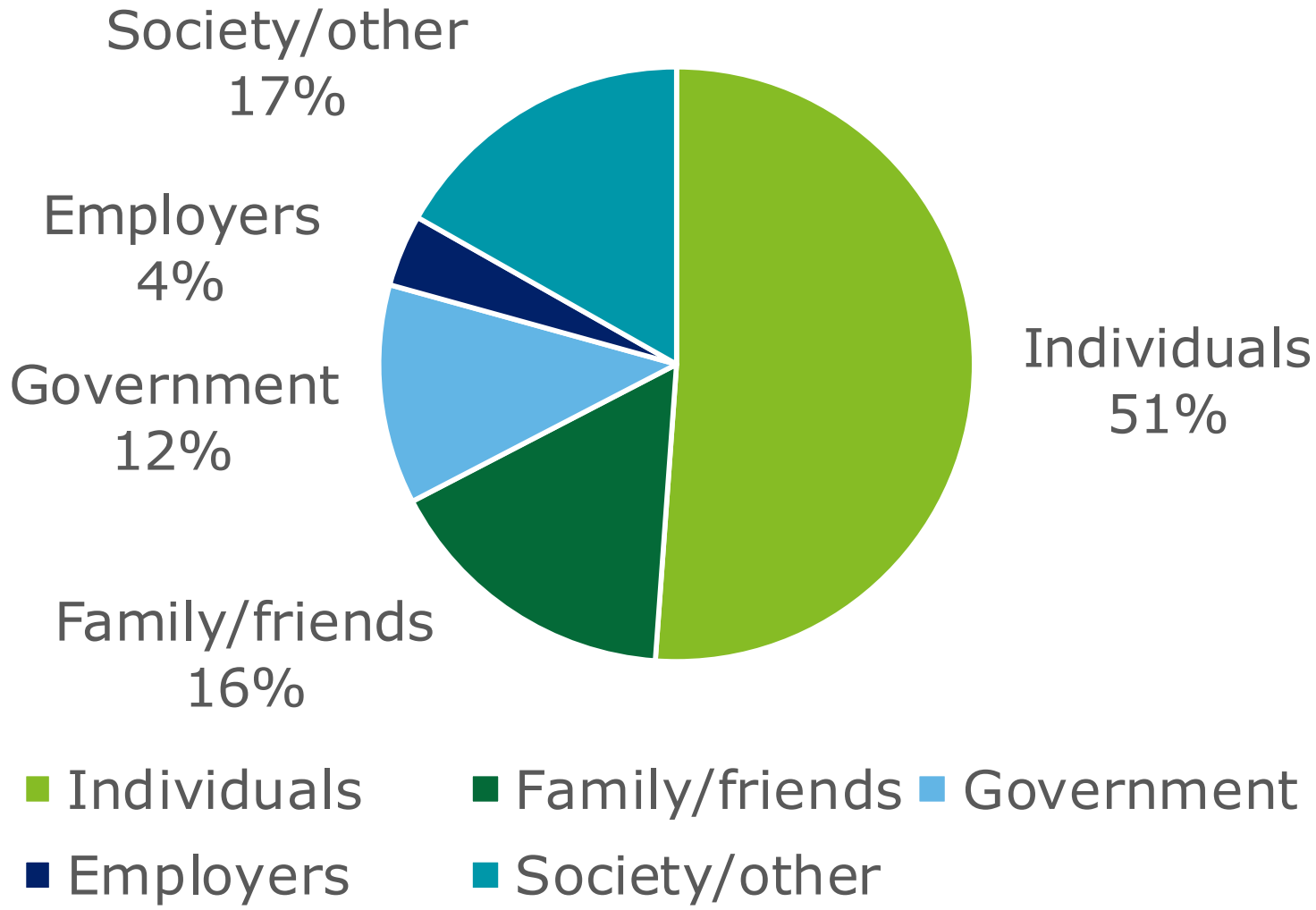
Source: Deloitte Access Economics analysis.

Table 11.2: Total costs of IRDs (€ million, 2019) in the RoI by cost type

Cost type	Percentage of total cost (%)	Cost
Wellbeing costs	32.3	16.0
Productivity costs	18.9	9.4
Deadweight losses	16.6	8.2
Other costs	14.2	7.0
Informal carer costs	13.6	6.7
Health system costs	4.5	2.2
Total IRDs	**100.0**	**49.5**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

Chart 11.3: Proportion (%) of total costs of IRDs (2019) in the RoI by payer



Source: Deloitte Access Economics analysis.

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Appendix A Additional information on survey results

This appendix details the survey questionnaire distributed to persons living with an IRD and/or the parents of children (under 18) living with an IRD.

The questionnaire comprised 12 modules:

1. About you
2. Your current condition
3. Work
4. Education
5. Management of your condition – health care providers
6. Management of your condition – medications and supplements
7. Management of your condition – vision aids and modifications and travel
8. Formal care
9. Informal care
10. Government support
11. Other impacts of your condition
12. Impact of your child's IRD on your mental wellbeing – from your own perspective as a parent/ guardian.

Skip logic was incorporated into the programming of the survey to ensure only relevant questions were asked of participants, depending on the answers provided to previous questions.

The questions asked, answers available and results received for each question are outlined in this appendix. In instances where a low number of results were received, results are aggregated to protect participant privacy and confidentiality.

A.1. Introduction

Deloitte Access Economics (Australia) is assisting Retina International and its partner organisations to better understand the real impact of inherited retinal dystrophies (IRDs). This survey aims to evaluate the financial and social impact of IRDs.

The findings will inform two reports, one each for the UK and the Republic of Ireland that will estimate the socioeconomic impact of IRDs in the UK and Ireland. The reports, including the summary findings from this survey, will be published on the websites of Retina International and its partner organisations.

Information collected through this survey will inform knowledge and understanding of:

- the impact on the wellbeing of individuals affected and their families; and
- the economic cost of IRDs to health and social care, education and employment and carers.

A.1.1. Purpose of the study

You are invited to participate in an online survey, which is being conducted in order to better understand IRD impacts. The survey is open to people who have or are the parent/guardian of someone with any of the following conditions:

- Retinitis pigmentosa (RP)
- Leber congenital amaurosis (LCA)/early onset severe retinal dystrophy to LCA (LCA/EOSRD)
- Usher syndrome
- Stargardt disease
- Choroideremia
- X linked retinoschisis
- Achromatopsia
- Cone dystrophy
- Cone rod dystrophy
- Best disease.

This survey contains up to 12 sections called modules and may take approximately 50 minutes to complete.

This survey will collect personal information about you including demographic information (such as your age and sex) and details about your work and education. It will also collect personal information about you that may be considered special category (or "sensitive") personal information, including your ethnicity, details about your condition, how you manage your condition, your use of healthcare services and your wellbeing.

Your personal information will be used to estimate the economics costs of IRDs and to describe the characteristics of groups of people (not individuals) who have or are the parent/guardian of someone with a diagnosed IRD.

Do you consent to Retina International and associated partners (IRD COUNTS- a consortium of patient organisations and industry partners advocating on behalf of the IRD community) to contact you in the future for further relevant research?

- Yes
- No

A.1.2. Confidentiality

Your personal information and special category information collected as part of this survey will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

While we use a third party survey platform provider to assist us in administering this survey, this provider is bound by strict confidentiality and privacy obligations. This means that your information will only be accessed by authorised personnel where required for the purpose of administering the survey and conducting the analysis described above.

A.1.3. The Legal basis for processing personal information

Before you complete this survey you will be asked to provide your consent to the collection and processing of your personal information and special category information for the purpose described above. Your consent will then form the legal basis upon which we are able to process your information.

A.1.4. Voluntary participation/right to refuse or withdraw

Your participation in this survey is voluntary; and you can withdraw at any time if you change your mind. If you decide to withdraw your consent by exiting the survey mid-way through, your responses will not be recorded.

You have various rights in relation to your personal information, including the right to seek access to, or to correct,

your information (for more information, please see our Privacy Statement).

If you are located in Europe, you also have the right to:

- ask that we delete personal information that we hold about you, or restrict the way in which we use your personal information;
- withdraw consent to our processing of your personal information; and
- obtain and/or move your personal information to another service provider.

However, we may still be required to retain a copy of certain information where it is necessary to comply with applicable laws or professional standards.

A.1.5. Contact details should you experience any unsettled feelings during this survey

If you experience any unsettled feelings while completing this survey, please contact SAMARITANS who provide confidential support in Ireland or the UK for free from any phone on 116 123. If you have any concerns about your IRD care and management, please contact your general practitioner/preferred health provider.

Fighting Blindness Ireland has a free counselling service for people and families living with sight loss.

The contact details for participants in Ireland are by email, insight@fightingblindness.ie, or by phone 01 674 6496.

For any questions about the objectives of the survey, how your data will be used or to exercise any of your rights, please contact the Deloitte Privacy Officer at privacy@deloitte.com.au

For any other questions please contact: irds@deloitte.com.au

A.2. Eligibility and Consent

Who are you completing this survey for?

- Myself as a person with an IRD
- As the parent/guardian of a child (aged up to 18 years old) with IRD
- On behalf of an adult with IRD as their carer

If you would like to proceed with participating in this survey, please provide consent.

By providing consent you are telling us that you:

- Understand what you have read.
- You are 18 years or over.
- Consent to take part in the research project.
- Consent to the processing of your personal information for the purpose described in the introduction to this survey
- Consent to the processing of your health and other types of special category information for the purpose described in the introduction to this survey.

Please confirm you have read and understand the information provided. By selecting 'yes' you agree to your involvement in the survey to understand the real impact of IRDs.

- Yes, I voluntarily consent
- No, I do not consent

A.3. Preliminary questions

Which of the following best describes how you will respond to this survey?

- As myself a person affected with an IRD
- As the parent/guardian of a child (aged up to 18 years old) with an IRD

Table A.1: Which of the following best describes how you will respond to this survey? (n=76) (RoI specific)

Participant type	Count (n)	Percentage (%)
Myself as a person with an IRD	52	68.4
As the parent/guardian of a child (aged up to 18 years old) with IRD	24	31.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

A.4. Module 1: About you

Which IRD are you diagnosed with?

- Retinitis pigmentosa (RP)
- Leber congenital amaurosis (LCA)
- Usher syndrome
- Stargardt disease
- Choroideremia
- X linked retinoschisis
- Achromatopsia
- Cone dystrophy
- Cone rod dystrophy
- Best disease

Table A.2: Which IRD are you diagnosed with? (n=76) (RoI specific)

Participant condition	Count (n)	Percentage (%)
RP	38	50.0
Stargardt disease	13	17.1
Other	12	15.8
Cone rod dystrophy	8	10.5
Usher	5	6.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What form of retinitis pigmentosa (RP) are you diagnosed with?

- Autosomal dominant RP
- Autosomal recessive RP
- X linked RP
- Unsure

Table A.3: What form of retinitis pigmentosa (RP) are you diagnosed with? (n=38) (RoI specific)

Participant condition	Count (n)	Percentage (%)
Unsure	25	65.8
Autosomal dominant RP	7	18.4
X linked RP	4	10.5
Autosomal recessive RP	2	5.3
Total	**38**	**100.0**

Source: Deloitte Access Economics analysis.

What was your biological sex at birth?
- Female
- Male
- Prefer not to say

Table A.4: What was your biological sex at birth (n=76) (RoI specific)

Biological sex	Count (n)	Percentage (%)
Female	41	54.0
Male	35	46.1
Not stated	0	0.0
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What is your age (all ages)?
- 5 to 9
- 10 to 14
- 15 to 17
- 18 to 24
- 25 to 34

- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

Table A.5: What is your age (all ages)? (n=76) (RoI specific)

Age	Count (n)	Percentage (%)
Under 18	24	31.6
18-24	6	7.9
25-34	5	6.6
35-44	11	14.5
45-54	11	14.5
55-64	11	14.5
65-74	8	10.5
75+	0	0.0
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What is your ethnicity?

- White including: English/Welsh/Scottish/Northern Irish/British/Irish/Irish Traveller/Other White background
- Asian/Asian British/Asian Irish including: Indian/Pakistani/Bangladeshi/Chinese/Any other Asian background
- Black/African/Caribbean/Black Irish/Black British including: African/Caribbean/Any other Black/African/Caribbean background
- Mixed/Multiple ethnic groups including: White and Black Caribbean/White and Black African/White and Asian/Any other Mixed/Multiple ethnic background

- Other ethnic group

Table A.6: What is your ethnicity? (n=76) (RoI specific)

Participant ethnicity	Count (n)	Percentage (%)
White including: English/Welsh/Scottish/Northern Irish/British/Irish/Irish Traveller/Other White background	73	96.1
Non-white	3	4.0
Total	**76**	**100**

Source: Deloitte Access Economics analysis.

A.5. Module 2: Your current condition

Which of these best describes the vision (if any) you have remaining?

- No vision
- Light perception only (or shadows only)
- Some useful central vision
- Good central vision
- Some useful peripheral vision
- Good peripheral vision
- I still have good overall vision
- Other – please specify

Table A.7: Which of these best describes the vision (if any) you have remaining? (n=76) (RoI specific)

Participant condition	Count (n)	Percentage (%)
Some useful central vision	30	56.6
Good central vision	26	49.1
Some useful peripheral vision	11	20.8
Good peripheral vision	10	18.9
I still have good overall vision	7	13.2
Light perception only (or shadows only)	3	5.7
No vision	1	1.9
Total	**53**	**100**

Source: Deloitte Access Economics analysis. Note "Other" responses were reclassified into the relevant categories. This question allowed for the selection of multiple answers, hence, the percentages did not sum to 100.

Are you registered as legally blind with the National Council for the Blind (NCBI)?

- Yes, I am registered as legally blind (Qualifying for registration requires that your best corrected visual acuity is equal to or less than 6/60 in the better eye or your field of vision is limited, the widest diameter of vision subtending an angle of not greater than 20 degrees)
- No, my degree of sight loss does not meet the criteria
- No, I have chosen not to be registered

Table A.8: Are you registered as legally blind with the National Council for the Blind (NCBI)? (n=76) (RoI specific)

Participant condition	Count (n)	Percentage (%)
Yes, I am registered as legally blind (Qualifying for registration requires that your best corrected visual acuity is equal to or less than 6/60 in the better eye or your field of vision is limited, the widest diameter of vision subtending an angle of not greater than 20 degrees)	46	60.5
No, my degree of sight loss does not meet the criteria	25	32.9
No, I have chosen not to be registered	5	6.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Has a doctor or specialist said that you have hearing loss?

- Yes, mild hearing loss (hearing impairment in the better ear of 20 to 34 dBHL)
- Yes, moderate hearing loss (hearing impairment in the better ear of 35 to 64 dBHL)
- Yes, severe hearing loss (hearing impairment in the better ear of 65 to 94 dBHL)
- Complete hearing loss (hearing impairment in the better ear of greater than 95 dBHL)
- Yes, unsure of level of hearing loss
- No

Table A.9: Has a doctor or specialist said that you have hearing loss? (n=5) (RoI specific)

Diagnosed hearing loss	Count (n)	Percentage (%)
Yes, any level of hearing loss	5	100.0
No	0	0.0
Total	**5**	**100.0**

Source: Deloitte Access Economics analysis.

Which of these best describes the hearing (if any) you have remaining?

- I do not have any hearing loss
- I do not have problems hearing what is said in a quiet environment, although I have difficulty following a conversation in a noisy environment
- I have difficulty hearing a normal voice in a quiet environment, and I have difficulty taking part in conversation in a noisy environment
- I can hear loud speech directly in my ear in a quiet environment, and I have great difficulty taking part in conversation in a noisy environment
- I am unable to hear in a quiet environment

Table A.10: Which of these best describes the hearing (if any) you have remaining? (n=5) (RoI specific)

Self-reported hearing	Count (n)	Percentage (%)
Any hearing difficulties	5	100.0
No	0	0.0
Total	**5**	**100.0**

Source: Deloitte Access Economics analysis.

A.6. Module 3: Work

Which of the following best describes your current state of work and study?

- Full time work
- Part time work
- Casual work (Not working on a regular basis)
- Underemployed (e.g. working part time but desiring full time work, or working in a role that does not use your skills or qualifications)
- Student only
- Retired (not working)
- Not employed and not studying, and looking for work
- Not employed, and not looking for work

Table A.11: Which of the following best describes your current state of work and study? (n=52) (RoI specific)

Employment/study status	Count (n)	Percentage (%)
Full time work	16	30.8
Retired (not working)	12	23.1
Not employed, and not looking for work	8	15.4
Part time work	5	9.6
Student only	5	9.6
Casual work (Not working on a regular basis)	3	5.8
Not employed and not studying, and looking for work	2	3.8
Underemployed (e.g. working part time but desiring full time work, or working in a role that does not use your skills or qualifications)	1	1.9
Total	**52**	**100.0**

Source: Deloitte Access Economics analysis.

What are your average weekly earnings after tax?
- 0 to 250
- 250 to 500
- 500 to 1,000
- 1,000 to 1,500
- 1,500 or more
- Prefer not to say

Table A.12: What are your average weekly earnings after tax? (n=25) (RoI specific)

Average weekly earnings (post tax, €)	Count (n)	Percentage (%)
0 to 250€	5	20.0
250 to 500€	7	28.0
More than 500€	12	48.0
Prefer not to say	1	4.0
Total	**25**	**100**

Source: Deloitte Access Economics analysis.

How many hours does your employer expect you to work in a typical 7 day week? If your hours vary, estimate the average. If you are self employed, estimate the number of hours you would consider a full work week. If you have more than one job, combine total number of hours for all jobs.

- Text response

Table A.13: How many hours does your employer expect you to work in a typical 7 day week? (n=25) (RoI specific)

	Average	Standard Deviation
Expected work hours	28	11

Source: Deloitte Access Economics analysis.

Now please think of your work experiences over the past 4 weeks. In the past 4 weeks, how many full and partial days of work (example 1.5 days) did you miss because of your IRD? Please include only days missed for your own health, not someone else's health.

- Text response

Table A.14: How many full and partial days of work did you miss because of your IRD? (n=25) (RoI specific)

	Average	Standard Deviation
Work days missed due to IRDs	0.1	0.4

Source: Deloitte Access Economics analysis.

About how many hours altogether did you work in the past 4 weeks? If you did not work at all in the past 4 weeks, enter "0".

- Text response

Table A.15: How many hours altogether did you work in the past 4 weeks? (n=25) (RoI specific)

	Average	Standard Deviation
Actual work hours	100.2	48.5

Source: Deloitte Access Economics analysis.

On a scale from 0 to 10 where 0 is the worst job performance anyone could have at your job and 10 is the performance of a top worker, how would you rate the usual performance of most workers in a job similar to yours?

- 0-10 scale

Table A.16: How would you rate the usual performance of most workers in a job similar to yours? (n=25) (RoI specific)

Perceived workplace performance rating	Count (n)	Percentage (%)
5	1	4.0
6	1	4.0
7	6	24.0
8	9	36.0
9	6	24.0
10	2	8.0
Total	**25**	**100.0**

Source: Deloitte Access Economics analysis.

Thinking about the impact of your IRD on your work, how would you rate your overall job performance on the days you worked during the past 4 weeks, using the same 0 to 10 scale?

- 0-10 scale

Table A.17: How would you rate your overall job performance on the days you worked during the past 4 weeks? (n=25) (RoI specific)

Self-assessed performance rating	Count (n)	Percentage (%)
10	3	12.0
9	3	12.0
8	8	32.0
7	3	12.0
6	4	16.0
5	2	8.0
4	2	8.0
Total	**25**	**100.0**

Source: Deloitte Access Economics analysis.

How would you compare your overall job performance on the days you worked during the past 4 weeks with the performance of most other workers who have a similar type of job?

- You were a lot better than other workers
- You were somewhat better than other workers
- You were a little better than other workers
- You were about average
- You were a little worse than other workers
- You were somewhat worse than other workers
- You were a lot worse than other workers

Table A.18: How would you compare your overall job performance on the days you worked during the past 4 weeks with the performance of most other workers who have a similar type of job? (n=25) (RoI specific)

Performance comparison	Count (n)	Percentage (%)
You were a lot worse than other workers	0	0.0
You were somewhat worse than other workers	1	4.0
You were a little worse than other workers	5	20.0
You were about average	8	32.0
You were a little better than other workers	3	12.0
You were somewhat better than other workers	7	28.0
You were a lot better than other workers	1	4.0
Total	**25**	**100.0**

Source: Deloitte Access Economics analysis.

Please select any modifications or aids that you currently use in your working environment specifically or including for your IRD.

- Books, including books with enlarged font, and audio-books
- Laptops (only select if specialised for you)
- Magnifiers
- Spoken word processor, verbal calculator or screen reader
- Braille display
- Ergonomic adaptations e.g. raised screens
- Modifications to mobile phones such as applications (apps)

- Other – please describe
- I do not use any additional items to support my work because I do not need them
- I do not use any additional items to support my work because they are not available

Table A.19: What modifications or aids used in the working environment specifically or including for an IRD? (n=25) (RoI specific)

Modification or aid	Count (n)	Percentage (%)
Magnifiers	9	36.0
I do not use any additional items to support my work because I do not need them	6	24.0
I do not use any additional items to support my work because they are not available	6	24.0
Modifications to mobile phones such as applications (apps)	5	20.0
Ergonomic adaptations e.g. raised screens	4	16.0
Spoken word processor, verbal calculator or screen reader	3	12.0
Books, including books with enlarged font, and audio-books	2	8.0
Laptops (only select if specialised for you)	2	8.0
Other – please describe	2	8.0
Braille display	0	0.0
Total	**25**	**100.0**

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

Approximately how much money did you spend in the past year on items related to your condition to assist you with your working?

- Text response

Table A.20: Approximately how much money did you spend in the past year on items related to your condition to assist you with your working? (n=25) (RoI specific)

	Average (€)	Standard Deviation
Money spent on aids and modifications for work	13	71

Source: Deloitte Access Economics analysis.

A.7. Module 4: Education

Are you currently studying or learning?

- Yes
- No

Table A.21: Are you currently studying or learning? (n=76) (RoI specific)

Study Status	Count (n)	Percentage (%)
Not Studying	44	57.9
Studying	32	42.1
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Where are you currently learning?

- Higher education (university)
- Further education
- Secondary education/post primary education
- Primary education
- Pre school/early childhood education
- Other education provider

Table A.22: Where are you currently learning? (n=32) (RoI specific)

Study Status	Count (n)	Percentage (%)
Primary education	13	40.6
Secondary education/post primary education	11	34.4
Higher education (university)	3	9.4
Further education	3	9.4
Preschool/early childhood education	1	3.1
Other education provider	1	3.1
Total	**32**	**100.0**

Source: Deloitte Access Economics analysis.

About how many hours altogether did you spend at your place of learning in the past 4 weeks?

- Text response

Table A.23: About how many hours altogether did you spend at your place of learning in the past 4 weeks? (n=22) (RoI specific)

	Average	Standard Deviation
Hours	72.47	47.28

Source: Deloitte Access Economics analysis.

How many hours do you spend on education related activities (e.g. studying, completing homework and/or assignments, research etc.) outside of your place of learning in a typical 7 day week? If it varies, estimate the average.

- Text response

Table A.24: How many hours do you spend on education related activities (e.g. studying, completing homework and/or assignments, research etc.) outside of your place of learning in a typical 7 day week? (n=32) (RoI specific)

	Average	Standard Deviation
Hours	8.73	7.93

Source: Deloitte Access Economics analysis.

In the past 4 weeks how many full and partial days of class (example 1.5 days) did you miss because of your IRD? Please include only days missed for your own health, not someone else's health.

- Text response

Table A.25: In the past 4 weeks how many full and partial days of class (example 1.5 days) did you miss because of your IRD? (n=32) (RoI specific)

	Average	Standard Deviation
Hours	0.31	0.64

Source: Deloitte Access Economics analysis.

Please select any modifications or aids that you currently use in your learning environment to assist with your learning.

- Books, including books with enlarged font and audio-books
- Laptops (only select if specialised for you)
- Magnifiers
- Spoken word processor, verbal calculator or screen reader
- Braille display
- Ergonomic adaptations e.g. raised screens
- Modifications to mobile phones such as applications (apps)
- Other – please describe
- I do not use any additional items to support my learning because I do not need them
- I do not use any additional items to support my learning because they are not available

Table A.26: What modifications or aids used in the learning environment specifically for an IRD? (n=32) (RoI specific)

Modification or aid	Count (n)	Percentage (%)
Magnifiers	15	46.9
Books, including books with enlarged font, and audio-books	13	40.6
Laptops (only select if specialised for you)	13	40.6
Other – please describe	8	25.0
Modifications to mobile phones such as applications (apps)	7	21.9
Ergonomic adaptations e.g. raised screens	5	15.6
Spoken word processor, verbal calculator or screen reader	4	12.5
Braille display	2	6.3
I do not use any additional items to support my work because I do not need them	0	0.0
I do not use any additional items to support my work because they are not available	0	0.0

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

Approximately how much money did you spend in the past year on items related to your condition to assist you with your learning?

- Text response

Table A.27: Approximately how much money did you spend in the past year on items related to your condition to assist you with your learning? (n=76) (RoI specific)

	Average (€)	Standard Deviation
Money spent on aids and modifications for learning	58	137

Source: Deloitte Access Economics analysis.

Do you receive additional support from a special needs teacher/assistant in your learning environment?

- Yes
- No

Table A.28: Do you receive additional support from a special needs teacher/assistant in your learning environment? (n=32) (RoI specific)

Special needs teacher/assistant	Count (n)	Percentage (%)
No	18	23.7
Yes	14	18.4
Total	**32**	**100.0**

Source: Deloitte Access Economics analysis.

On average, approximately how many hours per week do you receive additional support from a special needs assistant?

- Text response

Table A.29: How many hours per week do you receive additional support from a special needs assistant? (n=32) (RoI specific)

	Average	Standard Deviation
Hours	10.79	15.52

Source: Deloitte Access Economics analysis.

A.8. Module 5: Management of your condition – health care providers

Have you seen any health providers specifically for or relating to the management of your IRD in the last year?

- Yes
- No
- Unsure

Table A.30: Have you seen any health providers specifically for or relating to the management of your IRD in the last year? (n=76) (RoI specific)

Health system utilisation (total this year)	Count (n)	Percentage (%)
Yes	46	60.5
No	29	38.2
Unsure	1	1.3
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

When was the last time you saw a health provider specifically for or relating to the management of your IRD?

- 1 to 2 years
- 2 to 3 years
- 4 or more years
- Unsure

Table A.31: When was the last time you saw a health provider specifically for or relating to the management of your IRD? (n=29) (RoI specific)

Health system utilisation (total)	Count (n)	Percentage (%)
4 or more years	12	41.4
1 to 2 years	11	37.9
2 to 3 years	4	13.8
Unsure	2	6.9
Total	**29**	**100.0**

Source: Deloitte Access Economics analysis.

Which health providers have you seen for management specifically or including for your IRD in the last year?

- General practitioner
- Ophthalmologist
- Optometrist/optician
- Eye Clinic Liaison Officer (ECLO)
- Sight support volunteer
- Psychologist, psychiatrist or counsellor
- Genetic counsellor
- Occupational therapist
- Hospital emergency department
- Admitted to hospital as an inpatient
- Specialist outpatient clinic or unit
- Habilitation, Rehabilitation specialist or service, or low vision specialist
- Other – please describe
- Unsure

Table A.32:Which health providers have you seen for management specifically or including for your IRD in the last year? (n=46) (RoI specific)

Health System Utilisation (specific)	Count (n)	Percentage (%)
Ophthalmologist	37	80.4
Specialist outpatient clinic	17	37.0
Optometrist	16	34.8
General practitioner	6	13.0
Psychologist	5	10.9
Genetic counsellor	5	10.9
Sight support volunteer	3	6.5
Habilitation specialist	3	6.5
Eye clinic liaison officer	2	4.3
Emergency department	2	4.3
Occupational therapist	1	2.2
Admitted to hospital (inpatient)	0	0.0

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

Approximately how often do you attend appointments with your general practitioner specifically for or related to your IRD?

- Weekly
- Fortnightly
- Monthly
- Every 3 to 6 months
- Yearly
- Every 2 years
- Never

Table A.33: How often do you attend appointments with health providers specifically for or related to your IRD? (n=46) (RoI specific)

Health System Utilisation (visits)	Visits per year (n)
Psychologist	18.3
Eye clinic liaison officer	3.0
General practitioner	1.5
Sight support volunteer	1.5
Specialist outpatient clinic	1.4
Habilitation specialist	1.3
Ophthalmologist	1.1
Optometrist	1.0
Genetic counsellor	1.0
Occupational therapist	1.0
Emergency department	0.8
Admitted to hospital (inpatient)	0.0

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

Approximately how much money did your last visit to your health provider cost you out of pocket, after refunds, reimbursements and financial support?

- Text response

Table A.34: Approximately how much money did your last visit to your health provider cost you out of pocket, after refunds, reimbursements and financial support? (n=46) (RoI specific)

Health System Utilisation (cost)	Average (€)
Optometrist	49.38
Ophthalmologist	42.03
Psychologist	22.00
General practitioner	19.17
Genetic counsellor	14.00
Sight support volunteer	6.67
Eye clinic liaison officer	0.00
Occupational therapist	0.00
Emergency department	0.00
Admitted to hospital (inpatient)	0.00
Specialist outpatient clinic	0.00
Habilitation specialist	0.00

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

Approximately how long does it take for you to travel one way to your doctor/clinician for management of your IRD? Estimate this time for the doctor/clinician you visit most often for your condition.

- Less than 15 minutes
- Between 15 minutes and 30 minutes
- Between 30 minutes and an hour
- Between 1 hour and 2 hours
- Greater than 2 hours

Table A.35: Approximately how long does it take for you to travel one way to your doctor/clinician for management of your IRD? (n=47) (RoI specific)

Average hours spent travelling to medical appointments	Count (n)	Percentage (%)
Between 1 hour and 2 hours	16	34.0
Between 30 minutes and an hour	13	27.7
Between 15 minutes and 30 minutes	9	19.1
Greater than 2 hours	7	14.9
Less than 15 minutes	2	4.3
Total	**47**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how much money does it usually cost you per appointment to travel (e.g. either using public transport or a car) to your doctor/clinician for management of your IRD? Please estimate any accommodation, public transport or petrol costs before any refunds, reimbursements and financial support were received. If you are unsure please answer not applicable.

- Text response

Table A.36: How much money (€) does it usually cost you per appointment to your doctor? (n=33) (RoI specific)

	Average (€)	Standard Deviation
Average cost of the last medical appointment	31.06	43.14

Source: Deloitte Access Economics analysis.

Do you take time off work or education to attend these appointments?

- Yes, for all of my appointments
- Yes, for about three quarters of my appointments
- Yes, for about half of my appointments
- Yes, for about one quarter of my appointments
- No, I do not take time off work or education to attend my appointments

Table A.37: Do you take time off work or education to attend these appointments? (n=47) (RoI specific)

Time off for appointments (total)	Count (n)	Percentage (%)
Yes, for all of my appointments	25	53.2
No, I do not take time off work or education to attend my appointments	14	29.8
Yes, for about three quarters of my appointments	4	8.5
Yes, for about one quarter of my appointments	3	6.4
Yes, for about half of my appointments	1	2.1
Total	**47**	**100.0**

Source: Deloitte Access Economics analysis.

Do you attend consultations alone or with a friend, family member or carer?

- I attend consultations alone
- I attend consultations with a friend or family member
- I attend consultations with a formal carer
- I attend consultations with a friend or family member and a formal carer

Table A.38: Do you attend consultations alone or with a friend, family member or carer? (n=47) (RoI specific)

Appointment companion type	Count (n)	Percentage (%)
I attend consultations with a friend or family member	31	66.0
I attend consultations alone	14	29.8
I attend consultations with a formal carer	1	2.1
I attend consultations with a friend or family member and a formal carer	1	2.1
Total	**47**	**100.0**

Source: Deloitte Access Economics analysis.

Does your friend, carer or family member take time off work to attend these appointments?

- Yes, for all of my appointments
- Yes, for about three quarters of my appointments
- Yes, for about half of my appointments
- Yes, for about one quarter of my appointments

Table A.39: Does your friend, carer or family member take time off work to attend these appointments? (n=33) (RoI specific)

Appointment companion time off	Count (n)	Percentage (%)
Yes, for all of my appointments	22	66.7
Yes, for about one quarter of my appointments	5	15.2
Yes, for about three quarters of my appointments	4	12.1
Yes, for about half of my appointments	2	6.1
Total	**33**	**100.0**

Source: Deloitte Access Economics analysis.

How many appointments have you ever had with a genetic counsellor for or related to your IRD?

- None
- One
- Two
- Three or more
- Unsure

Table A.40: How many appointments have you ever had with a genetic counsellor for or related to your IRD? (n=76) (RoI specific)

Genetic counsellor appointments	Count (n)	Percentage (%)
None	53	69.7
One	15	19.7
Three or more	4	5.3
Two	1	1.3
Unsure	3	3.9
Total	**100.0**	**100.0**

Source: Deloitte Access Economics analysis.

Have you ever received a diagnostic genetic test specifically for or including for your IRD?

- Yes
- No
- Unsure

Table A.41: Have you ever received a diagnostic genetic test specifically for or including for your IRD? (n=76) (RoI specific)

Genetic test (lifetime)	Count (n)	Percentage (%)
Yes	45	59.2
No	28	36.8
Unsure	3	3.9
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Did you receive a diagnostic genetic test specifically for or including for your IRD within the last year?

- Yes
- No
- Unsure

Table A.42: Did you receive a diagnostic genetic test specifically for or including for your IRD within the last year? (n=45) (RoI specific)

Genetic test (within the year)	Count (n)	Percentage (%)
No	34	75.6
Yes	10	22.2
Unsure	0	0.0
Total	**45**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how much money did you spend on travel (e.g. airfares or petrol or bus fare or train fare or taxi fare) to receive the results of your genetic test? If you are unsure please answer not applicable.

- Text response

Table A.43: Did you receive a diagnostic genetic test specifically for or including for your IRD within the last year? (n=10) (RoI specific)

	Average (€)	Standard Deviation
Average cost of travel for genetic testing	36.50	42.30

Source: Deloitte Access Economics analysis.

Have any other members of your family seen a specialist to check for IRD symptoms?

- Yes
- No
- Unsure

Table A.44: Have any other members of your family seen a specialist to check for IRD symptoms? (n=76) (RoI specific)

Family specialist check	Count (n)	Percentage (%)
Unsure	53	69.7
Yes	22	28.9
No	1	1.3
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

How many of your family members have seen a specialist to check for IRD symptoms?

- 1
- 2
- 3
- 4
- 5 or more

Table A.45: How many of your family members have seen a specialist to check for IRD symptoms? (n=53) (RoI specific)

Family specialist check (number)	Count (n)	Percentage (%)
One	16	30.2
Two	15	28.3
Five or more	12	22.6
Three	5	9.4
Four	5	9.4
Total	**53**	**100.0**

Source: Deloitte Access Economics analysis.

Have your family members ever received a genetic test specifically or including for IRD?

- Yes
- No
- Unsure

Table A.46: Have your family members ever received a genetic test specifically or including for IRD? (n=56) (RoI specific)

Family genetic testing	Count (n)	Percentage (%)
Yes	35	66.0
No	11	20.8
Unsure	7	13.2
Total	**53**	**100.0**

Source: Deloitte Access Economics analysis.

A.9. Module 6: Management of your condition – medications and supplements

Do you use any medications to help manage your IRD?

- Yes
- No

Table A.47: Do you use any medications to help manage your IRD? (n=76) (RoI specific)

Medication usage	Count (n)	Percentage (%)
Yes	5	6.6
No	71	93.4
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What medications do you use to manage your IRD? Please separate any medications using commas.

- Text response

Table A.48: What medications do you use to manage your IRD? (n=5) (RoI specific)

Not for publication due to confidentiality implications.

Approximately how much money, on average, have you spent on medications specifically or including for your IRD, after refunds, reimbursements and financial supports in the last month? Please only include out of pocket costs.

- Text box

Table A.49: How much money have you spent on medications specifically or including for your IRD, after refunds, reimbursements and financial supports in the last month? (n=5) (RoI specific)

	Average (€)	Standard Deviation
Average cost of medication	14.60	17.10

Source: Deloitte Access Economics analysis.

Do you use any vitamins or nutritional supplements to help manage your IRD?

- Yes
- No

Table A.50:Do you use any vitamins or nutritional supplements to help manage your IRD? (n=76) (RoI specific)

Vitamin usage	Count (n)	Percentage (%)
No	61	80.3
Yes	15	19.7
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What vitamins or nutritional supplements do you use to manage your IRD? Please separate any vitamins or nutritional supplements using commas.

- Text response

Table A.51: What vitamins or nutritional supplements do you use to manage your IRD? (n=15) (RoI specific)

Not for publication due to confidentiality implications.

Approximately how much money, on average, have you spent on vitamins or nutritional supplements specifically or including for your IRD, after refunds, reimbursements and financial supports in the last month? Please only include out of pocket costs.

- Text response

Table A.52: How much money have you spent on vitamins or nutritional supplements specifically or including for your IRD in the last month? (n=15) (RoI specific)

	Average (€)	Standard Deviation
Average cost of vitamins	27.47	17.94

Source: Deloitte Access Economics analysis.

A.10. Module 7: Management of your condition – vision aids and modifications and travel

In the last year, approximately how much money have you spent on the following aids and modifications? If you do not use the vision aid please answer not applicable.

- Magnifying glasses
- Contrast enhancing filters
- Green or blue blocking sunglasses
- High vision lamps

Table A.53: In the last year, approximately how much money have you spent on the following aids and modifications? (n=76) (RoI specific)

Aid or Modification	Count (n)	Percentage (%)	Average (€)
High vision lamps	49	64.5	27.78
Magnifying glasses	47	61.8	24.15
Green or blue blocking sunglasses	44	57.9	49.66
Contrast enhancing filters	42	55.3	7.14

Source: Deloitte Access Economics analysis.

Are you a guide dog owner?
- Yes
- No

Table A.54: Are you a guide dog owner? (n=76) (RoI specific)

Guide dog ownership	Count (n)	Percentage (%)
No	73	96.1
Yes	3	3.9
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how many days in total did you spend learning with a trained professional to work with your guide dog? If you did not receive any training please answer not applicable.
- Text response

Table A.55: Approximately how many days in total did you spend learning with a trained professional to work with your guide dog (n=9) (UK and RoI combined)

Guide dog owners	Average (days)
Average training time	16.38

Source: Deloitte Access Economics analysis.

Approximately how much money have you spent caring for your guide dog in the last month?
- Text response

Table A.56: Approximately how much money have you spent caring for your guide dog in the last month? (n=9) (UK and RoI combined)

Guide dog owners	Average (€)
Money spent for your guide dog in the last month	101.48

Source: Deloitte Access Economics analysis.

Do you use a 'white' cane to aid your mobility?
- Yes
- No

Table A.57: Do you use a 'white' cane to aid your mobility? (n=76) (RoI specific)

White cane	Count (n)	Percentage (%)
No	52	68.4
Yes	24	31.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how many days in total did you spend learning with a trained professional to use your cane? If you did not receive any training please answer not applicable

- Text response

Table A.58:How many days in total did you spend learning with a trained professional to use your cane? (n=76) (RoI specific)

White cane users	Average (days)
Average training time	7.33

Source: Deloitte Access Economics analysis.

Do you use the aid of a mini guide or other electronic mobility devices (GPS or sensor devices)?

- Yes
- No

Table A.59: Do you use the aid of a mini guide or other electronic mobility devices (GPS or sensor devices)? (n=76) (RoI specific)

GPS or Mini guide	Count (n)	Percentage (%)
No	68	89.5
Yes	8	10.5
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

What was the approximate cost of this device? If you are unsure please answer not applicable.

- Text response

Table A.60: What was the approximate cost of this device? (n=8) (UK and RoI combined)

	Average (€)
GPS or Mini guide cost	360.40

Source: Deloitte Access Economics analysis.

Approximately how many hours did you spend training with the instructor for your mobility device? If you did not receive any training please answer not applicable.

- Text response

Table A.61: Approximately how many hours did you spend training with the instructor for your mobility device?] (n=8) (RoI specific)

	Average (days)
GPS or Mini guide cost training time	0

Source: Deloitte Access Economics analysis.

Do you have customised door frames or light switches in your home specifically or including for your IRD?

- Yes
- No

Table A.62: Do you have customised door frames or light switches in your home specifically or including for your IRD? (n=76) (RoI specific)

Customised door frames or light switches	Count (n)	Percentage (%)
No	71	93.4
Yes	5	6.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

If you have customised door frames or light switches in your home specifically or including for your IRD, please estimate the cost of this modification. If you are unsure please answer not applicable.

- Text response

Table A.63: If you have customised door frames or light switches in your home specifically or including for your IRD? (n=5) (UK and RoI combined)

	Average (€)
Customised door frames or light switches	149.51

Source: Deloitte Access Economics analysis.

Do you have customised bathtubs, showers or other bathroom modifications in your home specifically or including for your IRD?

- Yes
- No

Table A.64: Do you have customised bathtubs, showers or other bathroom modifications in your home specifically or including for your IRD? (n=76) (RoI specific)

Bathroom modifications	Count (n)	Percentage (%)
No	75	98.7
Yes	1	1.3
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

If you have customised bathtubs, showers or other bathroom modifications in your home specifically or including for your IRD, please estimate the cost of these modifications. If you are unsure please answer not applicable.

- Text response

Table A.65: If you have customised bathtubs, showers or other bathroom modifications in your home specifically or including for your IRD, please estimate the cost of these modifications. (n=3) (UK and RoI combined)

	Average (€)
Customised bathtubs, showers or other bathroom modifications cost	2088.67

Source: Deloitte Access Economics analysis.

Provide an estimate of the number, if any, of the following items that you use at home specifically for your IRD

- Magnifying mirrors
- High intensity lamps
- Book alternatives (large print or audiobooks)
- Handheld magnifiers
- Tactile or large print labels
- Large keyboards
- Screen magnification technology

- Screen reading software
- Portable note takers
- Customised clocks, watches or timers
- Other

Table A.66:Provide an estimate of the number, if any, of the following items that you use at home specifically for your IRD (n=76) (RoI specific)

Aid or modification	Count (n)	Percentage (%)
Handheld magnifiers	34	44.74
Screen magnification technology	32	42.11
Book alternatives	31	40.79
High intensity lamps	20	26.32
Screen reading software	20	26.32
Magnifying mirrors	16	21.05
Customised clocks or timers	8	10.53
Large keyboards	5	6.58
Portable note takers	5	6.58
Tactile or large print labels	3	3.95

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

On average, approximately how often do you use public transport for reasons other than medical appointments because of your IRD?

- More than twice per day
- Twice per day
- Once per day
- A few times per week
- Once per week
- Once every fortnight
- Once per month
- Once every three months or infrequently
- Never, I do not use public transport
- Never, I am still able to drive
- Unsure

Table A.67: How often do you use public transport for reasons other than medical appointments because of your IRD? (n=67, children were not asked this question) (RoI specific)

Public transport frequency (non-IRD purpose)	Count (n)	Percentage (%)
A few times per week	12	22.6
Twice per day	9	17.0
Once every three months or infrequently	6	11.3
More than twice per day	5	9.4
Once per week	5	9.4
Unsure	5	9.4
Never, I do not use public transport	4	7.5
Never, I am still able to drive	3	5.7
Once per day	3	5.7
Once per month	1	1.9
Once every fortnight	0	0.0
Total	**67**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how much money have you spent on public transport in the last month for reasons other than medical appointments because of your IRD? Please estimate these costs before refunds, reimbursements and financial support were received. If you are unsure please answer not applicable.

- Text response

Table A.68: Approximately how much money have you spent on public transport in the last month for reasons other than medical appointments because of your IRD? (n=67) (RoI specific)

	Average (€)	Standard Deviation
Average spend on public transport in the last month for non-IRD reasons	85.73	123.84

Source: Deloitte Access Economics analysis.

A.11. Module 8: Formal care

Do you have a formal carer (a person who is paid to give care) to assist you with your activities of daily living specifically or including for your IRD?

- Yes
- No

Table A.69: Do you have a formal carer (a person who is paid to give care) to assist you with your activities of daily living specifically or including for your IRD? (n=76) (RoI specific)

Formal care	Count (n)	Percentage (%)
No	70	92.1
Yes	6	7.9
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how many hours per week do you receive assistance from a formal carer specifically or including for your IRD?

- Less than 5 hours
- 5 to 9 hours
- 10 to 19 hours
- 20 to 29 hours
- 30 to 39 hours

- 40 hours or more

Table A.70: Approximately how many hours per week do you receive assistance from a formal carer specifically or including for your IRD? (n=8) (UK and RoI combined)

Formal care hours	Count (n)	Percentage (%)
Less than 5 hours	2	25
5 to 9 hours	3	37.5
10 to 19 hours	1	12.5
20 to 29 hours	1	12.5
40 hours or more	1	12.5
Total	**8**	**100.0**

Source: Deloitte Access Economics analysis.

A.12. Module 9: Informal care

Do you receive any assistance from an informal carer? An informal carer includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person without payment for the care given. If so, from whom? (Please identify your primary informal carer if you have more than one informal carer).

- Spouse
- Family member or relative
- Friend or other informal carer
- I do not receive any assistance from an informal carer

Table A.71: Do you have a formal carer (a person who is paid to give care) to assist you with your activities of daily living specifically or including for your IRD? (n=76) (RoI specific)

Informal carer type	Count (n)	Percentage (%)
I do not receive any assistance from an informal carer	34	44.7
Spouse	24	31.6
Family member or relative	15	19.7
Friend or other informal carer	3	3.9
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Approximately how many hours per week do you receive assistance from an informal carer?

- Less than 5 hours
- 5 to 9 hours
- 10 to 19 hours
- 20 to 29 hours
- 30 to 39 hours
- 40 hours or more

Table A.72: Approximately how many hours per week do you receive assistance from an informal carer? (n=42) (RoI specific)

Informal care hours	Count (n)	Percentage (%)
Less than five 5	16	38.1
5-9	9	21.4
10-19	4	9.5
20-29	3	7.1
30-39	1	2.4
40+	9	21.4
Total	**42**	**100.0**

Source: Deloitte Access Economics analysis.

What is the sex/gender of your informal carer? (Please choose the option as it applies to your primary informal carer if you have more than one informal carer)

- Male
- Female
- Other/unsure

Table A.73: What is the sex/gender of your informal carer? (n=42) (RoI specific)

Informal carer gender	Count (n)	Percentage (%)
Female	33	78.6
Male	9	21.4
Total	**42**	**100.0**

What is the approximate age of your informal carer? (Please choose the option as it applies to your primary informal carer if you have more than one informal carer and guess if you are unsure exactly)

- 15 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

Table A.74: What is the approximate age of your informal carer? (n=42) (RoI specific)

Informal carer age	Count (n)	Percentage (%)
15-24	0	0.0
25-34	3	7.1
35-44	10	23.8
45-54	13	31.0
55-64	9	21.4
65-74	6	14.3
75+	1	2.4
Total	**42**	**100.0**

Is your informal carer employed and if so, in what capacity? (Please choose the option as it applies to your primary informal carer if you have more than one informal carer).

- Full time work
- Part time work
- Casual work (Not working on a regular basis)

- Underemployed (e.g. working part time but desiring full time work; working in a role that does not use their skills or qualifications)
- Retired
- My informal carer is a student
- My informal carer is not employed, and not looking for work
- My informal carer is not employed, and is looking for work

Table A.75: Is your informal carer employed and if so, in what capacity? (n=42) (RoI specific)

Informal carer employment	Count (n)	Percentage (%)
Full time work	12	28.6
My informal carer is not employed, and not looking for work	9	21.4
Retired	9	21.4
Part time work	7	16.7
Casual work (Not working on a regular basis)	2	4.8
My informal carer is not employed, and is looking for work	2	4.8
Underemployed (e.g. working part time but desiring full time work; working in a role that does not use their skills or qualifications)	1	2.4
Total	**42**	**100.0**

Source: Deloitte Access Economics analysis.

Does your informal carer receive any government support specifically or including for your IRD? If so, which of the following forms of assistance does your informal carer receive?

- Carer's allowance
- Carer's Benefit
- Carer's Support Grant
- Other – please specify
- Unsure
- My informal carer does not receive any government support for my condition

Table A.76: Does your informal carer receive any government support specifically or including for your IRD? (n=42) (RoI specific)

Government Payment	Count (n)	Percentage (%)
My informal carer does not receive any government support for my condition	32	76.2
Carer's allowance	5	11.9
Other – please specify	4	9.5
Carer's Support Grant	2	4.8
Unsure	1	2.4
Carer's Benefit	0	0.0

Source: Deloitte Access Economics analysis.
Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

A.13. Module 10: Government support

Do you currently receive any government support specifically or including for your IRD? If so, which of the following forms of assistance do you receive?

- Blind Pension
- Blind Welfare Allowance
- Free Travel Pass
- Disability Allowance
- Blind Persons Tax Credits
- Guide Dog Allowance
- Job Seekers Benefit
- Living Alone Increase
- Household Benefits Package
- Other – please specify
- Unsure
- I do not receive any government support for my condition

Table A.77: Do you currently receive any government support specifically or including for your IRD (n=76) (RoI specific)

Government Payment	Count (n)	Percentage (%)
Free Travel Pass	43	56.6
Blind Persons Tax Credits	23	30.3
Disability Allowance	13	17.1
Blind Welfare Allowance	6	7.9
Blind Pension	5	6.6
Invalidity Pension	4	5.3
Domiciliary Care Allowance	4	5.3
Living Alone Increase	2	2.6
Household Benefits Package	2	2.6
Guide Dog Allowance	1	1.3
Illness Benefit	1	1.3
Job Seekers Benefit	0	0.0

Source: Deloitte Access Economics analysis. Note: This question allowed for the selection of multiple answers, hence, the percentages do not sum to 100.

A.14. Module 11: Other impacts of your condition

Have you ever experienced feelings of depression because of your IRD?

- Yes
- No

Table A.78: Have you ever experienced feelings of depression because of your IRD? (n=76) (RoI specific)

Experience of depression	Count (n)	Percentage (%)
Yes	48	63.2
No	28	36.8
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Have you ever experienced feelings of anxiety because of your IRD?

- Yes
- No

Table A.79: Have you ever experienced feelings of anxiety because of your IRD? (n=76) (RoI specific)

Experience of anxiety	Count (n)	Percentage (%)
Yes	65	85.5
No	11	14.5
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Have you ever experienced feelings of another mental health condition because of your IRD?

- Yes, please describe
- No

Table A.80: Have you ever experienced feelings of another mental health condition because of your IRD? (n=76) (RoI specific)

Experience of other mental health conditions	Count (n)	Percentage (%)
No	67	88.2
Yes	9	11.8
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Have any of your close family members ever experienced feelings of depression, anxiety, or another mental health condition as a result of your IRD?

- Yes
- No

Table A.81: Have any of your close family members ever experienced feelings of depression, anxiety, or another mental health condition as a result of your IRD? (n=76) (RoI specific)

Family experience of other mental health conditions	Count (n)	Percentage (%)
Yes	44	57.9
No	32	42.1
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

On a scale of 1 to 5 with 5 being strongly agree and 1 being strongly disagree, please answer the following statement. I feel frustrated from the lack of awareness and support for IRDs.

- 1 - I strongly disagree that I feel frustrated from the lack of awareness and support for IRDs.

- 2 - I disagree that I feel frustrated from the lack of awareness and support for IRDs.
- 3 - I neither agree nor disagree that I feel frustrated from the lack of awareness and support for IRDs.
- 4 - I agree that I feel frustrated from the lack of awareness and support for IRDs.
- 5 - I strongly agree that I feel frustrated from the lack of awareness and support for IRDs.

Table A.82: Feeling of frustration from the lack of awareness and support for IRDs (n=76) (RoI specific)

Frustration	Count (n)	Percentage (%)
1 – I strongly disagree that I feel frustrated	3	5.7
2 - I disagree that I feel frustrated	4	7.5
3 - I neither agree nor disagree	8	15.1
4 - I agree that I feel frustrated	19	35.8
5 - I strongly agree that I feel frustrated	18	34.0
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Do you experience any financial stress because of your IRD?
- Yes
- No
- Unsure

Table A.83: Do you experience any financial stress because of your IRD? (n=76) (RoI specific)

Experience of other mental health conditions	Count (n)	Percentage (%)
No	38	50.0
Yes	33	43.4
Unsure	5	6.6
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

Have you experienced social isolation because of your IRD?
Social isolation is a state of complete or near complete lack of contact between an individual and society.

- Yes
- No
- Unsure

Table A.84: Have you experienced social isolation because of your IRD? (n=76) (RoI specific)

Experience of social isolation	Count (n)	Percentage (%)
Yes	34	44.7
No	32	42.1
Unsure	10	13.2
Total	**76**	**100.0**

Source: Deloitte Access Economics analysis.

A.15. Module 12: Impact of your child's IRD on your mental wellbeing – from your own perspective as a parent/ guardian:

Have you (the parent/guardian) ever experienced feelings of depression due to your caring requirements for your child with an IRD?

- Yes
- No

Table A.85: Have you (the parent/guardian) ever experienced feelings of depression due to your caring requirements for your child with an IRD (n=24) (RoI specific)

Experience of depression	Count (n)	Percentage (%)
Yes	12	50.0
No	12	50.0
Total	**24**	**100.0**

Source: Deloitte Access Economics analysis.

Have you ever experienced feelings of anxiety due to your caring requirements for your child with an IRD?

- Yes
- No

Table A.86: Have you ever experienced feelings of anxiety due to your caring requirements for your child with an IRD? (n=24) (RoI specific)

Experience of anxiety	Count (n)	Percentage (%)
Yes	18	75.0
No	6	25.0
Total	**24**	**100.0**

Source: Deloitte Access Economics analysis.

Have you ever experienced feelings of another mental health condition due to your caring requirements for your child with an IRD?

- Yes, please specify
- No

Table A.87: Have you ever experienced feelings of another mental health condition due to your caring requirements for your child with an IRD? (n=24) (RoI specific)

Experience of other mental health conditions	Count (n)	Percentage (%)
No	22	91.7
Yes	2	8.3
Total	**24**	**100.0**

Source: Deloitte Access Economics analysis.

[Parent] On a scale of 1 to 5 with 5 being strongly agree and 1 being strongly disagree, please answer the following statement. I feel frustrated from the lack of awareness and support for IRDs.

- 1 - I strongly disagree that I feel frustrated from the lack of awareness and support for IRDs.
- 2 - I disagree that I feel frustrated from the lack of awareness and support for IRDs.
- 3 - I neither agree nor disagree that I feel frustrated from the lack of awareness and support for IRDs.
- 4 - I agree that I feel frustrated from the lack of awareness and support for IRDs.
- 5 - I strongly agree that I feel frustrated from the lack of awareness and support for IRDs.

Table A.88: Parent feeling of frustration from the lack of awareness and support for IRDs (n=24) (RoI specific)

Frustration	Count (n)	Percentage (%)
1 – I strongly disagree that I feel frustrated	1	1.3
2 - I disagree that I feel frustrated	3	3.9
3 - I neither agree nor disagree	5	6.6
4 - I agree that I feel frustrated	6	7.9
5 - I strongly agree that I feel frustrated	9	11.8
Total	**24**	**100.0**

Source: Deloitte Access Economics analysis.

Appendix B Additional information on prevalence

B.1. Summary of approach

A systematic literature review was undertaken to estimate the prevalence of the 10 IRDs included in this study. A targeted search of the PubMed and Cochrane Library databases, using key search terms, produced 34 potential publications for full text review. These were further refined to 14 publications that informed this estimate of the prevalence of these IRDs. Articles were then prioritised for inclusion if they met either of the following criteria:

- The publication provided a population-based prevalence estimate of at least one of the 10 included IRDs.
- The publication utilised national registry data to capture prevalence in a comparable country to the RoI.

Given the potential for double-counting where overlapping classification of individual IRDs may occur between different studies, publications providing a more comprehensive list of the included conditions were prioritised.

Publications considered at full text review are detailed in Appendix 0, along with the prevalence rates reported and the reason for their inclusion or exclusion as an input into this analysis.

B.2. Overall prevalence

Literature providing population prevalence estimates of IRDs (overall or condition-specific) is limited. Recent and nationwide prevalence estimates for IRDs in the RoI were not identified. National registry data on the prevalence of five out of the 10 IRDs was identified from a population-based study conducted in Denmark.

This population-based cross-sectional registry study of the prevalence of generalised retinal dystrophy, encompassing a group of hereditary degenerations of the human retina, was based on the Danish Retinitis Pigmentosa Registry (Bertelsen

et al, 2014). The condition-specific overarching population prevalence rates, summarised in Table B.1:, were available from Bertelsen et al (2014) and included in this analysis.

In the absence of other data, a retrospective epidemiologic observational study of Best disease conducted in Denmark was used to inform the estimated population prevalence of Best disease in the RoI (Bitner et al, 2012). Based on this article, the overall prevalence of Best disease in Denmark in 2011 was estimated to be 1.5 per 100,000 people (0.0015%) (Table B.1:).

Table B.1: Overall published population prevalence estimates for RP, LCA/EOSRD, cone-rod dystrophy, choroideremia, Usher syndrome, and Best disease

IRD	Source	Prevalence estimate (%)
RP	Bertelsen et al (2014)	0.0154
LCA/EOSRD	Bertelsen et al (2014)	0.0024
Cone-rod dystrophy	Bertelsen et al (2014)	0.0012
Choroideremia	Bertelsen et al (2014)	0.0004
Usher syndrome	Bertelsen et al (2014)	0.0039
Best disease	Bitner et al (2012)	0.0015

Source: Bertelsen et al (2014) and Bitner et al (2012).

In order to estimate the prevalence of the remaining conditions (cone dystrophy, Stargardt disease, XLRS, and achromatopsia), the relative prevalence of these conditions was derived from published results of the Target 5000 study conducted in Ireland (Dockery et al, 2017).

The Target 5000 research project aims to genetically characterise the estimated 5,000 people in Ireland with IRDs. Findings from approximately 750 persons living with an IRD as part of this target capture next-generation study have been published (Dockery et al, 2017).

Based on these results, it was estimated that RP, LCA/EOSRD, cone-rod dystrophy, choroideremia, and Usher syndrome collectively represented 60.6% of the included IRDs. Based on this proportion, and the estimated prevalence for these conditions and Best disease, it was calculated that there were a total of 1,522 prevalent cases in the RoI. This represents an overall prevalence rate of 0.03%.

Condition-specific prevalence was calculated for the remaining conditions based on a study of the relative prevalence of a subset of IRDs conducted over a 21-year period in a specialised outpatient clinic in Southern France (Bocquet et al, 2013). Based on this study, population prevalence rates were derived by applying the relative proportion of conditions reported to the overarching prevalence estimate of 0.03%. These derived prevalence rates are summarised in Table B.2:.

Table B.2: Overall derived population prevalence estimates for cone dystrophy, Stargardt disease, XLRS, and achromatopsia

IRD	Prevalence estimate (%)
Cone dystrophy	0.0013
Stargardt disease	0.0032
XLRS	0.0007
Achromatopsia	0.0011

Source: Deloitte Access Economics' analysis based on Bertelsen et al (2014), Bitner et al (2012), Dockery et al (2017), and Bocquet et al (2013).

B.3. Age and sex distribution

Our approach to estimating the prevalence of IRDs in the RoI utilised age and sex specific rates, where they were available from the literature. Data from the eyeGENE registry, which reports on a sample of 4,635 participants with various IRDs in the United States, was used to inform the sex distribution where there was no peer-reviewed academic literature located. It was assumed that the sex distribution of cone dystrophy matched the profile of cone-rod dystrophy reported based on the eyeGENE registry (National Eye Institute, 2019).

Table B.3: Sources used to estimate age and sex specific prevalence rates by IRD

IRD	Source	Male (%)	Female (%)
RP	Bundey and Crews, 1984 (UK), condition-specific	52.3	47.7
LCA/EOSRD	Haim et al, 1992 (Denmark), condition-specific	55.0	45.0
Cone-rod dystrophy	eyeGENE registry (National Eye Institute, 2019), condition-specific	61.2	38.8
Choroideremia	eyeGENE registry (National Eye Institute, 2019), condition-specific	84.4	15.6
Usher syndrome	Sadeghi et al, 2004 (Sweden), condition-specific	46.8	53.2
Best disease	eyeGENE registry (National Eye Institute, 2019), condition-specific	45.3	54.7
Cone dystrophy	eyeGENE registry (National Eye Institute, 2019), condition-specific	61.2	38.8
Stargardt disease	eyeGENE registry (National Eye Institute, 2019), condition-specific	42.3	57.7

IRD	Source	Male (%)	Female (%)
XLRS	eyeGENE registry (National Eye Institute, 2019), condition-specific	95.3	4.7
Achromatopsia	eyeGENE registry (National Eye Institute, 2019), condition-specific	44.8	55.2

Source: Deloitte Access Economics' analysis based on Bundey and Crews (1984), Haim et al (1992), eyeGENE registry (National Eye Institute, 2019), and Sadeghi et al (2004).

B.4. Results

Overall prevalence of IRDs in the RoI disaggregated by age and sex is summarised in Table B.4: The prevalence of IRDs increases progressively with age until the 60-69 year age group, after which prevalence gradually declines. Overall prevalence is slightly higher in males (52.4%) compared to females (47.6%).

Table B.4: Prevalence of IRDs in the RoI (2019) by age and sex

	Male		Female		Total	
Age group	**Rate (%)**	**Cases**	**Rate (%)**	**Cases**	**Rate (%)**	**Cases**
0-9	0.0106	36	0.0099	32	0.0103	68
10-19	0.0243	82	0.0224	72	0.0233	154
20-29	0.0328	98	0.0293	87	0.0311	184
30-39	0.0326	112	0.0280	102	0.0303	215
40-49	0.0385	138	0.0347	127	0.0366	264
50-59	0.0449	133	0.0408	123	0.0428	256
60-69	0.0480	112	0.0422	100	0.0451	213
70-79	0.0400	61	0.0329	53	0.0363	114
80+	0.0402	27	0.0295	29	0.0338	56
Total	**0.0329**	**798**	**0.0294**	**725**	**0.0311**	**1,522**

Source: Deloitte Access Economics analysis.
Note: Components may not sum to totals due to rounding.

B.5. Summary of sources informing overall prevalence estimates by condition

Table B.5: Summary of sources informing overall prevalence estimates of RP

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0237
Grondahl (1987)	Norway	Excluded – age of study	0.0227
Bundey and Crews (1984)	UK	Excluded – age of study; outpatient setting	0.0206
Peterlin et al (1992)	Slovenia	Excluded – age of study; outpatient setting; generalisability of study population	0.0166
Bertelsen et al (2014)	Denmark	Included	0.0154

Source: Deloitte Access Economics research.

Table B.6: Summary of sources informing overall prevalence estimates of LCA/EOSRD

Study	Country	Reason	Prevalence estimate (%)
Bertelsen et al (2014)	Denmark	Included	0.0024
Haim et al (1992)	Denmark	Excluded – age of study	0.0018

Source: Deloitte Access Economics research.

Table B.7: Summary of sources informing overall prevalence estimates of code-rod dystrophy

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0045
Bertelsen et al (2014)	Denmark	Included	0.0012

Source: Deloitte Access Economics research.

Table B.8: Summary of sources informing overall prevalence estimates of choroideremia

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0006
Bertelsen et al (2014)	Denmark	Included	0.0004
Haim et al (1992)	Denmark	Excluded – age of study	0.0004

Source: Deloitte Access Economics research.

Table B.9: Summary of sources informing overall prevalence estimates of Usher syndrome

Study	Country	Reason	Prevalence estimate (%)
Hope et al (1997)	UK	Excluded – age of study; outpatient setting	0.0062
Spandau et al (2002)	Germany	Excluded – age of study; outpatient setting	0.0062
Rosenberg et al (1997)	Denmark	Excluded – age of study	0.0050
Bertelsen et al (2014)	Denmark	Included	0.0039
Grondahl (1987)	Norway	Excluded – age of study	0.0036
Sadeghi et al (2004)	Sweden	Excluded – age of study	0.0033
Haim et al (1992)	Denmark	Excluded – age of study	0.0031
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0015

Source: Deloitte Access Economics research.

Table B.10: Summary of sources informing overall prevalence estimates of Best disease

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0044
Bitner et al (2012)	Denmark	Included	0.0015

Source: Deloitte Access Economics research.

Table B.11: Summary of sources informing overall prevalence estimates of cone dystrophy

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study	0.0044
Dockery et al (2017); Bocquet et al (2013)	Ireland; France	Included (derived from distribution of IRDs)	0.001

Source: Deloitte Access Economics research.

Table B.12: Summary of sources informing overall prevalence estimates of Stargardt disease

Study	Country	Reason	Prevalence estimate (%)
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0116
Orphanet (2019)	International	Excluded – primary sources and methods not reported	0.0100
Dockery et al (2017); Bocquet et al (2013)	Ireland; France	Included (derived from distribution of IRDs)	0.003

Source: Deloitte Access Economics research.

Table B.13: Summary of sources informing overall prevalence estimates of XLRS

Study	Country	Reason	Prevalence estimate (%)
Orphanet (2019)	International	Excluded – primary sources and methods not reported	0.0050
Puech et al (1991)	France	Excluded – age of study; outpatient setting	0.0036
Dockery et al (2017); Bocquet et al (2013)	Ireland; France	Included (derived from distribution of IRDs)	0.001

Source: Deloitte Access Economics research.

Table B.14: Summary of sources informing overall prevalence estimates of achromatopsia

Study	Country	Reason	Prevalence estimate (%)
Orphanet (2019)	International	Excluded – primary sources and methods not reported	0.0027
Dockery et al (2017); Bocquet et al (2013)	Ireland; France	Included (derived from distribution of IRDs)	0.001

Source: Deloitte Access Economics research.

Appendix C Additional information on other costs

C.1. Descriptions of welfare payment types

C.1.1. Blind Pension

The Blind Pension is a means-tested form of welfare available to people aged between 18 and 66 years who are either blind or visually impaired. Recipients receive a base payment of €203.0 with additional amounts available for those with dependents (Citizens Information Board, 2019a).

C.1.2. Blind Welfare Allowance

The Blind Welfare Allowance is a means-tested payment to people, aged 18 and over, who are blind or visually impaired. This payment is received in addition to the Blind Pension or other form of financial assistance due to blindness/visual impairment (Citizens Information Board, 2019b).

C.1.3. Disability Allowance

The Disability Allowance is a means-tested weekly allowance paid to working age people who are substantially restricted in their capacity to undertake work due to a physical or mental disability. Recipients receive a base payment of €203.0 with additional amounts available for those with dependents (Citizens Information Board, 2019c).

C.1.4. Blind Person's Tax Credit

The Blind Person's Tax credit provides an annual personal income tax credit of €1,650 to individuals whose best corrected vision is less than 6/60 (Citizens Information Board, 2019d).

C.1.5. Living Alone Increase (LAI)

The LAI is a weekly payment for people of any age who receive certain other welfare payments, such as the Blind Pension, and are living alone. Recipients are entitled to a weekly payment of €9 (Citizens Information Board, 2019e).

C.1.6. Invalidity Pension

The Invalidity Pension is a weekly payment made to working age persons who are unable to work due to a long-term illness

or disability and are covered by social insurance. Individuals who qualify for the payment receive a weekly base of €208.5 with additional amounts available for those with dependents, however the amount is subject to taxation (Citizens Information Board, 2019f).

C.1.7. Illness Benefit

The Illness Benefit is a welfare payment made to individuals who are unable to work due to sickness or illness. To qualify, individuals must have made at least a minimum number of social insurance contributions since commencing work and within a given tax year (Citizens Information Board, 2019g).

C.1.8. Carer's Allowance

The Carer's Allowance is a payment available to low income individuals looking after a person who needs support because of age, disability or illness. Carers are entitled to a maximum weekly payment of €219.0 if caring for an individual aged under 66 or €257.00 if caring for an individual aged 66 and above. Additional amounts are available if caring for multiple people. In order to qualify for the Carer's Allowance, a carer must be living with or in a position to provide full-time care, aged 18 or older, and not engaged in more than 15 hours a week of study or employment (Citizens Information Board, 2019h).

C.1.9. Domiciliary Care Allowance (DCA)

The DCA is a monthly payment for a child under 16 years with a severe disability requiring ongoing care, substantially greater than the care usually required by a child of the same age. Qualified individuals receive a monthly amount of €309.50 (Citizens Information Board, 2019i).

C.1.10. Child Benefit

The Child Benefit is a monthly payment to the parents or guardians of children under 16 years of age. Parents/guardians can receive a payment per child under the age of 18 years if the child is in full-time education, full-time training or have a disability and cannot support themselves. Those eligible receive can €140 for each child (Citizens Information Board, 2019j).

C.1.11. Jobseeker's Benefit

Jobseeker's Benefit is a weekly payment to people who are out of work and are covered by social insurance (PRSI). To qualify, individuals must be unemployed, or have lost at least one day's employment and as a result be unemployed for at least 4 days out of 7 days. The amount received is dependent on previous AWE with additional amounts available for adult and/or child dependents.

C.1.12. Carer's Benefit

The Carer's Benefit is a form of welfare for insured people who leave the workforce to become full-time carers for those who may require it. Carer's can receive the payment for a total period of 104 weeks for each person being cared. Carer's are entitled to a maximum weekly payment of €220.0 with additional amounts available if caring for multiple people.

In order to qualify for the Carer's Benefit, a carer must have been recently employed, be living with or in a position to provide full-time care, aged between 16 and 66, and not engaged in more than 15 hours a week of study or employment.

C.1.13. Carer's Support Grant

The Carer's Support Grant is an annual payment made to carers. In order to receive the grant, individuals must be aged 16 or over, caring on a full-time basis, not working or studying more than 15 hours a week and receiving jobseeker's welfare. Qualified carers receive an annual, non-taxable payment of €1,700.

Limitation of our work

General use restriction

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