# Sight loss in Swindon Profile February 2015



Swindon Health and Wellbeing Board





### Contents

1.0 Summary	4
1.1 Prevalence	4
1.2 Costs	4
1.3 Major eye conditions	4
1.4 Children and young people	5
1.5 Service provision	5
1.6 Recommendations	5
2.0 Glossary	6
2.1 Ophthalmologist	6
2.2 Optometrist	6
2.3 Optician	6
2.4 Age-related Macular Degeneration (AMD)	6
2.5 Cataract	6
2.6 Glaucoma	6
2.7 Diabetic retinopathy	6
3.0 Introduction	7
3.1 Purpose	7
3.2 Key National Drivers and Policy	7
3.3 Local Population	8
3.4 Deprivation	9
3.5 Ethnicity	9
4.0 Sight loss – Prevalence and Incidence	10
4.1 Definitions of certification, registration and sight loss	10
4.2 Prevalence, CVIs and Registration	10
4.3 Children and young people	15
4.4 Older people	15
5.0 Projections	16
6.0 Sight threatening eye conditions	
6.1 AMD	
6.2 Glaucoma	18

6.3 Cataracts	19
6.4 Diabetic Retinopathy	20
6.5 Other conditions that can affect eye health	22
6.6 Inequalities	22
6.7 Additional disability	23
7.0 Health determinants	24
7.1 Risk factors for developing sight conditions	24
8.0 Support, Activities and Service Provision	25
8.1 NHS Sight Tests	26
8.2 Ophthalmology department	27
8.3 Social care	27
8.4 Voluntary Sector	28
8.5 Equipment	29
8.6 Additional impacts of sight loss	29
9.0 Recommendations	30
References	31

# 1.0 Summary

### **1.1 Prevalence**

There are an estimated 5,300 people living with sight loss in Swindon, of these only 620 are registered as of March 2014. One of the major risk factors for sight loss is age. In Swindon there will be an estimated 61% increase in those aged over 65 by 2030<sup>1</sup> and therefore an estimated 9220 people living with sight loss in the area by 2030.<sup>2</sup>

Many people with sight loss are able, with support, to maintain a good quality of life. However, sight loss is associated with a number of co-morbidities, for example, stroke, neurological conditions, learning disabilities, dementia, falls and depression. Poorer health outcomes are often seen in people who are affected by these conditions and are visually impaired compared to those who have the condition but are not visually impaired. Therefore, reducing avoidable sight loss, ensuring rapid diagnosis, appropriate and timely treatment and suitable support is vital.

### 1.2 Costs

The costs of visual impairment include not only the direct costs associated with healthcare but also the indirect costs, such as unpaid care, adaptations and unemployment. Programme budgeting data suggest total ophthalmology healthcare expenditure for Swindon was £9 million in 2011/12, (£45.36 per person) whilst the indirect costs of sight loss have been estimated at £15 million (£71.58 per person). Cataract surgery in Swindon cost £1.2 million in 2013/14.<sup>3</sup>

### 1.3 Major eye conditions

The major sight conditions in the UK are: age-related macular degeneration (AMD), glaucoma, cataract and diabetic retinopathy.

• AMD is the leading cause of certifiable sight loss and 45% of new Certificate of Visual Impairments (CVIs) in 2012/13 are due to AMD in people aged 65 and over.<sup>4</sup> An estimated 7,010 people in Swindon are living with the early stages of AMD including drusen; 513 people are living with late stage dry AMD; and 1,061 people are living with late stage wet AMD.<sup>5</sup> This equates to potentially about 13% of the Swindon population aged 50 and over affected.

• Glaucoma is an asymptomatic disease that damages the optic nerve and can lead to blindness. Estimates suggest there may be around 1,756 people in Swindon with glaucoma, a further 7,297 suspected cases and 4,160 people with ocular hypertension, which is a condition that increases the risk of developing glaucoma.<sup>5</sup>

• The prevalence of cataract has been estimated at 1,863 people in Swindon in 2013.<sup>6</sup> The condition was responsible for 1,482 admissions to hospital in 2013/14.<sup>7</sup>

• Diabetic retinopathy is a complication of diabetes and estimates suggest there were 12,750 adults living with diabetes in Swindon in 2013.<sup>3</sup> Between 2010/11 and 2012/13 incidence has increased by 16% in Swindon, a rate of increase above the national average.<sup>4</sup> Given the current and on-going rise of diabetes in the UK, diabetic retinopathy is expected to have a major impact on eye services in the future. Diabetic retinopathy screening is an effective way of detecting the disease as early as possible; in Swindon screening uptake was 80.8% in 2012/13.<sup>4</sup>

Low vision and uncorrected refractive error are also important eye health conditions. Estimates suggest there may be almost 2,637 people with impaired vision (binocular acuity <6/18) and approximately 2,247 people with low vision (binocular acuity <6/18 to 3/60) living in Swindon.<sup>6</sup>

### 1.4 Children and young people

Children with vision impairment have different needs from adults. In Swindon there were 91 children (aged <18) registered as blind or partially sighted as of March 2014.<sup>8</sup> However, this figure is likely to be an underestimate due to issues with registration data; estimates suggest the actual number could be over 50% higher. It is estimated that only 1 in 4 children under 16 will have a NHS sight test, which is lower than the England average, meaning that there may be a number of children with some degree of undiagnosed and uncorrected visual impairment.<sup>29</sup>

### **1.5 Service provision**

There are a range of service providers that provide eye services across Swindon borough, including optometrists, ophthalmology departments/hospital, GPs, community and voluntary sector and social care.

### **1.6 Recommendations**

This report presents a rapid profile of sight loss in Swindon. It identifies a number of recommendations that will be taken forward as part of the action plan to deliver the Vision 2020 Strategy in Swindon. The recommendations are:

- 1. Investigate why Certificate of Visual Impairment rates in Swindon are lower than elsewhere and ensure that people are aware of the benefits of registration when they have their CVI assessment
- 2. To increase the number of children accessing eye tests
- 3. Take into account the projected increase in the number of older people with potential sight loss when planning services both in terms of type of condition that may need treatment and diagnosis but also the nature and accessibility of provision.
- 4. Recognise the likely increase in people with co-morbidities with sight loss including dementia, and the needs of people with dual sensory loss.
- 5. Increase awareness of existing provision and support and ensure appropriate information is available once diagnosed, from providers, via Swindon Advice and Information Centre, and via MyCareMySupport.
- 6. Ensure that effective and in-depth mobility and enablement support (e.g. using a white stick, software support) and training are available to people with sight loss in Swindon in line with good practice guidelines.
- 7. To increase the proportion of people with diabetes who attend diabetic retinopathy screening to equal or exceed the England average
- 8. Raise awareness of the risk factors for sight loss conditions and prevention including lifestyle changes and regular sight tests.

# 2.0 Glossary

### 2.1 Ophthalmologist

An ophthalmologist — is a medical or osteopathic doctor who specialises in eye and vision care. An ophthalmologist diagnoses and treats all eye diseases, performs eye surgery and prescribes and fits eyeglasses and contact lenses to correct vision problems. Many ophthalmologists are also involved in scientific research on the causes and cures for eye diseases and vision disorders.

### 2.2 Optometrist

Optometrists are healthcare professionals who provide primary vision care ranging from sight testing and correction to the diagnosis, treatment, and management of vision changes. An optometrist is not a medical doctor. They are licensed to practice optometry, which primarily involves performing eye exams and vision tests, prescribing and dispensing corrective lenses, detecting certain eye abnormalities, and prescribing medications for certain eye diseases.

### 2.3 Optician

Opticians are technicians trained to design, verify and fit eyeglass lenses and frames, contact lenses, and other devices to correct eyesight. They use prescriptions supplied by ophthalmologists, who are medical doctors and surgeons or optometrists, but do not test vision or write prescriptions for visual correction. Opticians are not permitted to diagnose or treat eye diseases.

### 2.4 Age-related Macular Degeneration (AMD)

There are 2 main types of AMD, dry and wet. Dry AMD usually develops very slowly and usually takes a long time to get to its final stage. At its worst, dry AMD causes a blank patch in the central vision in both eyes. Wet AMD develops when the cells of the macula stop working correctly and the body starts growing new blood vessels to fix the problem. Wet can have a rapid onset and needs to be treated quickly in order to reduce the risk of severe loss of vision.

### 2.5 Cataract

These are cloudy patches that develop in the lens of your eye and can cause blurred or misty vision. Over time, the cataracts become worse and start affecting vision.

#### 2.6 Glaucoma

This is a condition which can affect sight, usually due to build-up of pressure within the eye. It is often asymptomatic. It can damage the optic nerve and the nerve fibres from the retina.

#### 2.7 Diabetic retinopathy

This is a common complication of diabetes. It occurs when high blood sugar levels damage the cells at the back of the eye, the retina. If it isn't treated, it can cause blindness.

# **3.0 Introduction**

### 3.1 Purpose

There are 1.86 million people in the UK living with sight loss. By 2020 this number is predicted to increase by 22 per cent and will double to almost four million people by the year 2050. The increase can be attributed chiefly to an ageing population; over 80 per cent of sight loss occurs in people aged over 60 years. The Government have identified the importance of ensuring that people do not lose their sight unnecessarily. The Public Health Outcomes Framework for England includes an indicator for the prevention of sight loss, and recognises the link between sight loss and wider determinants of health.

This profile focuses on sight loss in general rather than specifically on access to ophthalmology services. The Clinical Commissioning Group (CCG) within Swindon is working on a service redesign programme for ophthalmology services.

This profile draws on the regional Eye Health Needs Assessment produced for Bristol, North Somerset, Somerset and South Gloucestershire (BNSSSG) by Lucy McCann on behalf of the Eye Health LPN and would like to acknowledge the benefit of that work.

### 3.2 Key National Drivers and Policy

**UK Vision Strategy.** The UK vision strategy was launched in 2008 in response to the World Health Assembly Resolution of 2003. In June 2013, the refreshed strategy, 2013-2018 Strategy, was launched with the following aims:

- 1. Everyone in the UK looks after their eyes and their sight;
  - a. Raise awareness and understanding of eye health, particularly focusing on people most at risk of eye disease
  - b. Encourage every individual to develop personal responsibility for their eye health and sight
  - c. Raise awareness of eye health and the impact of sight loss among health and social care practitioners and ensure the early detection of sight loss and prevention where possible.
- 2. Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all;
  - a. Improve the co-ordination, integration, reach and effectiveness of eye health and eye care services
  - b. Ensure that, when permanent sight loss occurs, emotional support, habilitation and/or rehabilitation will be provided in a timely fashion, enabling people to retain or regain their independence.
- 3. A society in which people with sight loss can fully participate
  - a. Improve attitudes, awareness and actions within education, employment and other services
  - b. Ensure that children and young people with sight impairment can take their place in society
  - c. Achieve improved compliance with equality legislation.<sup>10</sup>

**Public Health Outcomes Framework.** The Public Health Outcomes Framework Healthy lives, Healthy people: Improving outcomes and supporting transparency, sets out a vision for public health, desired outcomes and indicators that will help people understand how well public health is being improved and protected.<sup>4</sup> One of the 4 domains includes indicators to reduce the number of people living with preventable ill health and people dying prematurely. There are 4 indicators which relate to sight loss:

- Rate, per 100,000 population, of sight loss certifications (gathered from CVI data).
- Rate of sight loss certifications due to AMD.
- Rate of sight loss certifications due to Glaucoma
- Rate of sight loss certifications due to Diabetic eye disease

There are a further four indicators in the framework which may also be assisted by improvements in eye health:

- Falls and Injuries in the over 65s;
- Hip fractures in the over 65s;
- Self-reported wellbeing;
- Health related quality of life for older people.

**World Health Organization (WHO) VISION 2020.** It is a global initiative that aims to eliminate avoidable blindness by the year 2020 by strengthening national health-care systems and facilitating national capacity-building.<sup>11</sup>

**NHS Outcomes Framework**. The framework has 5 domains to cover effectiveness, experience and safety to enable commissioners to provide services in order to;

- Preventing people from dying prematurely (Domain 1)
- Enhancing quality of life for people with long term conditions (Domain 2)
- Helping people to recover from episodes of ill health or following injury (Domain 3)
- Ensuring people have a positive experience of care (Domain 4)
- Treating and caring for people in a safe environment and protecting them from avoidable harm (Domain 5)<sup>12</sup>

It is thought preventing sight loss will contribute to achieving each of these aims either directly or in directly.

### **3.3 Local Population**

A total of 214,037 people live in Swindon local authority area with similar numbers of men (106,804) and women (107,233).<sup>16</sup> 15% of people are aged over 65, and 2% over 85. Swindon has had 16% population growth between the 2001 and 2011 census and has the 12th biggest local authority population expansion in England and Wales and the largest in the south west. Milton Keynes is in the Nearest Neighbour Model from ONS area classifications and is widely used as a local authority comparator for Swindon. It will be used along with South West and England averages as a comparison throughout this profile.<sup>17</sup>

There is an association between age and the prevalence of sight loss. Nationally it is estimated that one in five people aged 75 and over are living with sight loss; compared to one in two aged 90 and over. Older people with sight loss are also much more likely to have

additional health conditions or disabilities.<sup>2</sup> In Swindon estimates suggest there are 763 people over the age of 65 living in care homes. This represents 3% of people aged over 65. Amongst the over 85's 11% of people live in a care home.<sup>18</sup>

Figure 1 shows Swindon has higher proportions in the younger age groups than the South West and England, however, they are lower than Milton Keynes proportions. These population proportions suggest Swindon would have lower rates of sight loss than the South West and England but slightly higher than Milton Keynes.

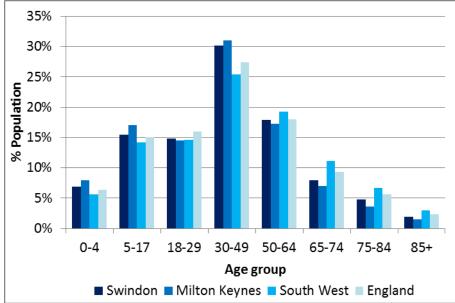


Figure 1. Population proportions by age group in Swindon, Milton Keynes, South West and England, 2013 mid-year estimate.

### **3.4 Deprivation**

17.4% of children in Swindon live in income deprived households, and 16.3% of those over 60 suffer from income deprivation. Multiple deprivation measures show concentrations in Swindon which are mirrored by those with poor health status.<sup>19</sup> Life expectancy is 7.2 years lower for men and 3.7 years lower for women in the most deprived areas of Swindon than in the least deprived areas.<sup>20</sup>

### 3.5 Ethnicity

The proportion of black and ethnic minority (BME) people in Swindon, in approximate terms, doubled from 8.5% (15,344 people) in 2001 to 15.4% (32,128 people) in 2011. 14.3% of Swindon's population belong to a BME community, with 11% of school children speaking English as a second language.<sup>21</sup>

Source: ONS

# 4.0 Sight loss – Prevalence and Incidence

### 4.1 Definitions of certification, registration and sight loss

#### Certification

A Certification of Vision Impairment (CVI) formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). Each CVI form is completed by a consultant ophthalmologist in an eye clinic, with a copy sent to the local social services department and providing a formal route to social care services. The other copy is sent to the Moorfields Eye Hospital that collects information to contribute to national statistics as seen in PHOF.

#### Registration

Upon receipt of a completed CVI form, social services in the local authority offer registration and other relevant advice and support. Registers of blind and partially sighted people are maintained by all local authorities to help them plan and deliver services. People that have a CVI can choose whether or not to be included in their local authority's register, registration is not automatic. For these reasons the data cannot be considered as definitive numbers of blind and partially sighted people in the local authority. The data is released every 3 years from HSCIC.

#### Sight loss

The RNIB Sight Loss Tool defines blindness (severe sight loss) as best-corrected visual acuity of <6/60 in the better-seeing eye. In the tool, partial sight is defined as best-corrected visual acuity of <6/12 to 6/60 in the better-seeing eye. This definition differs from that used in the CVI process. Further details about the methodology used to calculate this data can be found on the guidance notes for the tool.<sup>2</sup>

### 4.2 Prevalence, CVIs and Registration

There are an estimated 5,300 people living with sight loss in Swindon. The estimated prevalence is 2.5% (based on 2011 population), this is lower compared to than the England estimate of 2.95%.<sup>2</sup> However, this is lower than the number of people formally recognised as having sight loss. Over the last 3 years there has been a year on year reduction in the number of CVI's issued in Swindon (Table 1).

Table 1. Numbers of CVIs issued by year in Swindon, Milton Keynes, South West and
England 2010/11, 2011/12, 2012/13.

	Swindon	Milton Keynes	England
2010/11	96	132	22,228
2011/12	63	30	22,389
2012/13	58	34	22,647

Source: Public Health Outcomes Framework

In 2012/13, the certification rate in Swindon was 58 per 100,000 population, this is significantly lower than the England rate. The certification rate in Swindon decreased by 35.2% between 2010/11 and 2011/12 and by a further 8.7% by 2012/13 (Figure 2).

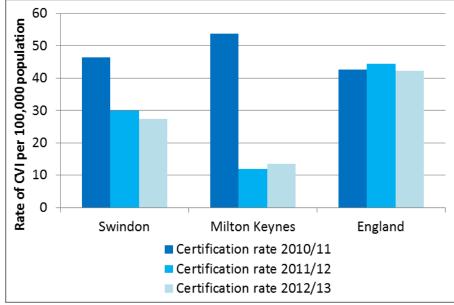


Figure 2. Rates of CVI in Swindon, Milton Keynes and England. 2010/11 to 2012/13

Source: Public Health Outcomes Framework

In total, 620 people are registered as living with severe sight loss (blind and partially sighted) following a CVI being completed. In Swindon, Milton Keynes and the South West the numbers of people being newly registered blind in 2013/14 have increased when compared to 2010/11. For partially sighted registrations, the numbers in Swindon, Milton Keynes and the South West have all decreased in 2013/14 compared to 2010/11 (Table 2).

Swi	Swindon Milton Keynes South West		West	England			
2010/	2013/	2010/	2013/	2010/	2013/	2010/	2013/
11	14	11	14	11	14	11	14
35	40	45	50	1,000	1,015	9,110	8,875
45	30	80	70	1,295	1,205	11,850	12,220
80	70	125	120	2,295	2,220	20,960	21,095
565	620	985	1,090	29,985	29,305	298,765	291,10 0
	2010/ 11 35 45 80	2010/       2013/         11       14         35       40         45       30         80       70	Swindon         Milton           2010/         2013/         2010/           11         14         11           35         40         45           45         30         80           80         70         125	Swindon         Milton Keynes           2010/         2013/         2010/         2013/           11         14         11         14           35         40         45         50           45         30         80         70           80         70         125         120	Swindon         Milton Keynes         South           2010/         2013/         2010/         2013/         2010/           11         14         11         14         11           35         40         45         50         1,000           45         30         80         70         1,295           80         70         125         120         2,295	SwindonMilton KeynesSouth West2010/2013/2010/2013/2010/2013/111411141114354045501,0001,015453080701,2951,20580701251202,2952,220	Swindon         Milton Keynes         South West         Engl           2010/         2013/         2010/         2013/         2010/         2013/         2010/         11         14         15         14         30         80         70         1,295         1,205         11,850         14

Table 2. Number of new registrations and total registrations of sight loss in Swindon,Milton Keynes, South West and England, 2010/11 and 2013/14.

Source: HSCIC

In March 2014, there were a total of 620 people registered as blind or partially sighted in Swindon. Using population data from 2013 (which is the latest available) and applying this to the new registrations for the year ending March 2014, (Table 2) a crude rate per 100,000

population can be calculated. Figure 3 shows rates of registrations have decreased in all areas.



Figure 3. Rate of new registrations per 100,000 population in Swindon, Milton Keynes, South West & England, 2010/11 and 2013/14.

The proportion of the population registered in Swindon is lower than in the Milton Keynes, South West and England (Table 3). This may reflect a decrease in the rate of certification combined with a potentially lower follow up from certification to register. It is not known whether the registrations in the past year are as a result of a certificate issued that year or further in the past. The person may decide they need more help with living with their sight loss and so would like to be included on the register in order to access more help and potential benefits.

South west and England, 2010/11 and 2013/14.					
	Proportion of registrations				
	to population				
	2010/11 2013/14				
Swindon	0.28%	0.29%			
Milton Keynes	0.41%	0.43%			
South West	0.57%	0.54%			
England	0.57%	0.54%			

Table 3. Proportion of people registered in the population for Swindon, Milton Keynes, South West and England, 2010/11 and 2013/14.

Source: HSCIC and ONS

In Milton Keynes, South West and England, the overall distribution of registrations between blind and partially sighted is about equal, with slight bias towards partially sighted registrations. However, in Swindon, the proportions are higher for the number of blind registrations compared to partially sighted (Table 4). This may indicate that people who are

Source: HSCIC and ONS

partially sighted are not being included on the register. Or that people are being included on the register later when sight loss is more severe.

	Blind	Partially
		Sighted
Swindon	60%	40%
Milton Keynes	47%	53%
South West	49%	51%
England	49%	51%

Table 4. Proportion of registrations between blind and partially sighted in 2014

Source: HSCIC

As reflected in the population composition, Swindon (and Milton Keynes) have a lower proportion of registrations in those over 75 compared to South West and England, and higher proportion in the under 75's, particularly in the under 65's (Table 5).

	Swi	indon	Milton Keynes		nes South West		England	
Age Group	Blind	Partially	Blind	Partially	Blind	Partially	Blind	Partially
Age Oloup	Binu	Sighted	Billu	Sighted	Binu	Sighted	Dinu	Sighted
0 to 4	0	0	0	0	115	100	735	630
5 to 17	5	10	20	20	280	430	3,540	4,630
18 to 49	60	45	120	105	1,675	1,590	19,570	18,210
50 to 64	50	40	85	70	1,485	1,315	17,580	15,400
65 to 74	45	25	65	65	1,310	1,340	14,040	14,565
75 or over	210	130	225	315	9,555	10,110	87,920	94,280
Total	e	520	1	,090	29	,305	291	,100

 Table 5. Age breakdown of registrations total up to March 2014.

Source: HSCIC

A higher rate of registrations in the younger age group may indicate that older age groups are not accessing the services they need in order to be registered, thereby skewing the proportion towards the younger age groups (Figure 4).

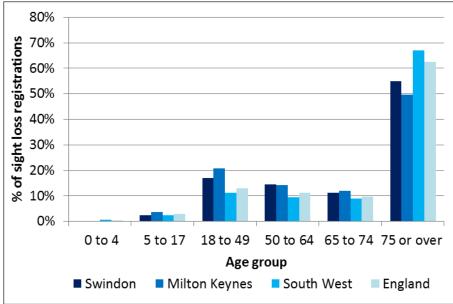
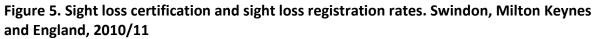


Figure 4. Percentage of sight loss registrations by age group, in Swindon, Milton Keynes, South West and England. Total up to March 2014

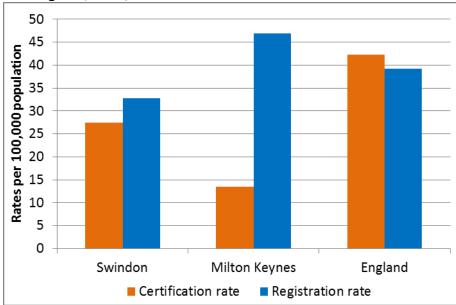
Figure 5 demonstrates in 2010/11 the certification rate was slightly higher than the registration rate in all areas. However, when looking at 2013/14, in Swindon the registration rate was higher than the certification rate. (Figure 6). This may be due to the rate of certifications being lower possibly due to decreased access of services.

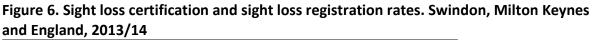




Source: Public Health Outcomes Framework and HSCIC

Source: HSCIC





Source: Public Health Outcomes Framework and HSCIC

### 4.3 Children and young people

It is estimated there are around 25,000 blind and partially sighted children and young people aged 0-16 in the UK, and 15,000 aged 17-25. Around half of these will have additional disabilities and/or special educational needs. Many of these children and young people will need help and support in order to maximise their potential in education and in other activities.<sup>2</sup> In Swindon there are an estimated 91 blind and partially sighted children aged 0-16 and 45 blind and partially sighted young people aged 17-25.<sup>3</sup> Table 5 shows only a fraction of this number are registered. There are 26 pupils with a statement of special education needs (SEN) or at School Action Plus with visual impairment as their primary SEN.<sup>2</sup> It is estimated that only 1 in 4 children under 16 will have a NHS sight test, which is lower than the England average, meaning that there may be a number of children with some degree of undiagnosed and uncorrected visual impairment.<sup>29</sup>

### 4.4 Older people

The prevalence of sight loss increases with age. One in five people aged 75 and over are living with sight loss; compared to one in two aged 90 and over. Older people with sight loss are also much more likely to have additional health conditions or disabilities. In Swindon there are an estimated 974 people aged 65 to 74; 1,429 people aged 75 to 84; and 1,485 people aged 85 and over living with sight loss in the local authority.<sup>2</sup> Approximately 20 per cent of people aged over 75 years and 50 per cent of people aged over 90 have significant sight loss and for many people correctly prescribed glasses could rectify this situation. It is important to ensure care home residents attend routine eye tests as conditions left undiagnosed and untreated sight loss can increase the risk of depression, falls and hip fractures, loss of independence and living in poverty.<sup>4</sup> In 2013/14 the estimated rate of sight tests amongst people over 60 is higher in Swindon than the England average, at 66,183 per 100,000 population.<sup>29</sup>

# **5.0 Projections**

It is well known that the UK is facing an aging population. In Swindon the over 65 age groups all see a percentage increase over 40% in each group by the year 2030 (Figure 7).

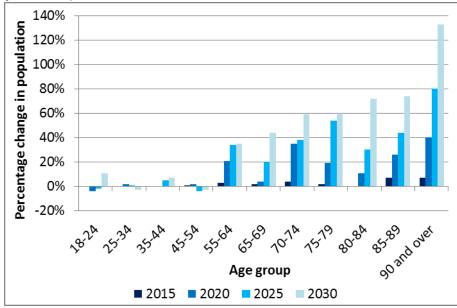


Figure 7. Projected percentage increases in population in Swindon by age group, (baseline year 2012) 2015, 2020, 2025 and 2030

The RNIB Sight Loss Tool, from where many of these projected prevalence figures have come from, utilises proven prevalence rates from either academic studies or observed current rates and applies them to the projected population. This may be an underestimate of future sight loss as these crude projections do not take changes in multi-morbidity into account such as higher alcohol consumption rates and increases in obesity, which leads to more diabetes diagnoses. It is solely the increase in the older population that is driving the prevalence of sight loss in the National prevalence tools and hence in this document. Table 6 demonstrates that estimated number of people affected by sight loss is expected to double by the year 2030.

Source: POPPI

Year		Swindon	Milton Keynes	South West	England
2011	Estimated number of people living with sight loss	5,300	5,370	186,010	1,564,340
	Estimated prevalence of sight loss	2.5%	2.2%	3.5%	3.0%
2020	Estimated number of people living with sight loss	6,950	7,370	227,340	1,903,330
	Estimated prevalence of sight loss	3.1%	2.7%	4.1%	3.4%
2030	Estimated number of people living with sight loss	9,220	10,430	291,480	2,419,730
	Estimated prevalence of sight loss	3.7%	3.5%	5.0%	4.0%

Table 6. Projected prevalence and number of people living with sight loss in Swindon,Milton Keynes, South West and England, 2011, 2020 and 2030.

Source: RNIB Sight Loss Tool

Of the people affected by sight loss, Table 7 shows the projected number of people registered blind or partially sighted will also double by the year 2030.

Table 7. Projected number of people registered blind or partially sighted in Swindon,
Milton Keynes, South West and England, 2011, 2020 and 2030.

Year	Swindon	Milton Keynes	South West	England
2011	620	610	22,920	187,740
2020	840	860	28,680	234,520
2030	1,160	1,300	38,470	310,900

Source: RNIB Sight Loss Tool

# 6.0 Sight threatening eye conditions

There are a number of people who are living with a sight threatening eye condition. This includes people who have experienced sight loss as a result of age-related macular degeneration, cataract, glaucoma and diabetic retinopathy. It also includes people with the early stages of these diseases who have not experienced any reduction in their vision at this point.

### 6.1 AMD

**Definition** – AMD is the most common cause of sight loss in people over the age of 65 – hence the name 'age-related macular degeneration'. The two most common forms of AMD are dry AMD and wet AMD. Dry AMD usually develops very slowly and usually takes a long time to get to its final stage. At its worst, dry AMD causes a blank patch in the central vision in both eyes. Wet AMD develops when the cells of the macula stop working correctly and the body starts growing new blood vessels to fix the problem. The condition can develop very quickly, making serious changes to central vision in a short period of time. Drusen are yellow deposits under the retina, whilst these do not cause AMD, it is more likely a person with drusen will go on to develop AMD. Treatment usually needs to be given quickly as if blood vessels are left to grow, the scarring and the sight loss it causes is usually permanent.<sup>22</sup>

**How many people are affected** – In Swindon (in 2011) it is estimated that 7,010 people are living with the early stages of AMD or drusen; 513 people are living with late stage dry AMD; and 1,061 people are living with late stage wet AMD.<sup>5</sup> These figures are calculated by applying a prevalence rate from a national model to the relevant population.

# Table 8. Rate of CVI due to AMD in Swindon, Milton Keynes, South West and England,2012/13.

	Swindon	Milton Keynes	England
Rate of CVI per 100,000 population aged over 65	85.7	40.7	104.4

Source: Public Health Outcomes Framework

**Treatment** - There is currently no cure for either type of AMD. With dry AMD, treatment is mostly based on helping a person make the most of their remaining vision, such as using magnifying lenses to help make reading easier. Wet AMD can be treated with a type of medication which aims to stop vision getting worse by helping prevent further blood vessels developing. Laser surgery can also be used to destroy abnormal blood vessels.<sup>22</sup>

### 6.2 Glaucoma

**Definition** – Glaucoma is a condition which can affect sight, usually due to build-up of pressure within the eye. It is often asymptomatic. Glaucoma often affects both eyes, usually to varying degrees. One eye may develop glaucoma quicker than the other. The eye ball contains a fluid called aqueous humour which is constantly produced by the eye, with any

excess drained though tubes. Glaucoma develops when the fluid cannot drain properly and pressure builds up, known as the intraocular pressure. This can damage the optic nerve and the nerve fibres from the retina.<sup>22</sup>

**How many people are affected** – In Swindon (in 2011) it is estimated 1,756 people are living with glaucoma. There are a further 7,297 suspected cases and 4,160 people with ocular hypertension, which is a condition that increases the risk of developing glaucoma (Table 10).<sup>5</sup>

# Table 9. Rate of CVI due to Glaucoma in Swindon, Milton Keynes, South West and England,2012/13.

	Swindon	Milton Keynes	England
Rate of CVI per 100,000	10.9	7.2	12.5
population aged over 40			

Source: Public Health Outcomes Framework

#### Table 10. Expected number of cases of Glaucoma in Swindon in 2011

	Mean estimate	High estimate	Low estimate	Suspects under 60	Suspects over 60	Total suspects	Ocular hypert- ension
Swindon (2011 population)	1,756	2,479	1,093	4,508	2,789	7,297	4,160
Prevalence	1.35%	1.91%	0.84%	5%	7%	5.61%	3.20%

Source: NEHEM

**Treatment** – Glaucoma can be treated with eye drops, laser treatment or surgery. Treatment aims to reduce the pressure in the affected eye, called intraocular pressure. Any damage to vision caused by glaucoma cannot be repaired. Laser treatment can be used to open up the blocked trabecular meshwork (drainage tubes) within the eye. A trabeculectomy is the most common type of glaucoma surgery. It involves removing part of the trabecular meshwork to allow fluid to flow through the eye's drainage system. People diagnosed with glaucoma are closely monitored to check for further damage to their vision. Appointments every one to four months or up to 12-24 months apart with an optometrist or an ophthalmologist are required.<sup>22</sup>

### 6.3 Cataracts

**Definition** – Cataracts are cloudy patches that develop in the lens of the eye and can cause blurred or misty vision. The lens is the transparent structure that sits just behind the pupil. It allows light to get to the back of the eye (retina). In some people, cataracts develop in the lens as they get older, stopping some of the light from reaching the back of the eye. Over time, the cataracts become worse and start affecting vision.

**How many people are affected** – In Swindon it is estimated that between 1,863 and 6,654 people are living with cataracts in 2013.<sup>3</sup>

	High estimate	Low estimate
Swindon (2013 population)	6,654	1,863
Prevalence	6.37%	1.78%

 Table 11. Expected number of cases of cataract in Swindon in 2013.

Source: NEHEM

In 2013/14 there were 1482 cases of cataract treated by Swindon service providers.<sup>7</sup>

**Treatment** – If the cataracts are mild, stronger glasses and brighter reading lights may be helpful for some time. However, cataracts get worse over time so it's likely that the person will need surgery as this is the only proven effective treatment. This will usually be recommended if loss of vision has a significant effect on daily activities, such as driving or reading.<sup>22</sup>

### 6.4 Diabetic Retinopathy

**Definition** – It is a common complication of diabetes which occurs when high blood sugar levels damage the cells at the back of the eye (known as the retina). If not treated, it can cause blindness. To work effectively, the retina needs a constant supply of blood, which it receives through a network of tiny blood vessels. Over time, a continuously high blood sugar level can cause the blood vessels to narrow, bleed or leak. This damages the retina and stops it from working. When the blood vessels in the central area of the retina (the macula) are affected, it's known as diabetic maculopathy. People may not realise their retina is damaged until the later stages, when vision becomes affected. Vision loss will probably be permanent at this late stage, and so diabetic eye screening is important.<sup>22</sup>

**How many people are affected** – In Swindon, in 2013, it is estimated that 3,570 people are living with background diabetic retinopathy; and 408 people are living with non-proliferative and proliferative diabetic retinopathy, which are later stages of the disease.<sup>3</sup>

Table 12. Rate of CVI due to Diabetic Eye Disease in Swindon, Milton Keynes, South West
and England, 2012/13.

	Swindon	Milton Keynes	England
Rate of CVI per 100,000	5.0	(Value supressed	3.5
population aged over 12		due small count)	

Source: Public Health Outcomes Framework

### Diabetic retinopathy screening

The NHS Diabetic Eye Screening Programme (NDESP) is responsible for ensuring that routine screening for diabetic retinopathy is offered to all people with diabetes aged 12 and over in England. More information about the programme can be found at <u>diabeticeye.screening.nhs.uk</u>.

	Swindon	Milton Keynes	South West	England
1.Estimated total number of people with diabetes 2013	12,750	14,149	356,800	3,314,477
2. Estimated prevalence of diabetes 2013	7.4%	7.2%	8.0%	7.6%
3. Recorded diabetes 2013/14	11,425	11,895	267,262	2,814,004
4. Prevalence of recorded diabetes 2013/14	6.57%	5.38%	5.86%	6.21%
5. Percentage of people that attended screening who were offered it 2012/13	80.8%	81.5%	83.4%	79.1%

Source: 1 & 2 RNIB Sight Loss Tool and ONS, 3, 4 & 5 Public Health Outcomes Framework

Figures from row 1 and 2 in Table 13 are from estimates calculated in the RNIB sight loss tool which are taken from the Health Survey England and applied to the 2013 population. This figure estimates the number of cases in the population diagnosed and also undiagnosed, which, when compared against recorded cases in rows 3 and 4, is higher. In the number of recorded cases, Swindon had the highest in the South West and is also increasing more than the England average over the last 3 years. Data for the first 3 quarters of 2013/14 suggest screening uptake of around 75%.<sup>36</sup>

There is a Quality Outcomes Framework (QOF) indicator on retinal screening which is the percentage of patients with diabetes, on the register, who have a record of retinal screening in the preceding 12 months. This was introduced in 2013/14 when Swindon had 79.5% of people with diabetes had had retinal screening (Table 14), however, it is not being carried forward.<sup>35</sup>

Number who	Total number	Number who	% screened	Total on	% screened
were	available to	were excepted	(excluding	register	of all on
screened	be screened	from screening	exceptions)		register
9,278	10,107	1,558	91.8%	11.665	79.5%

 Table 14. QOF registers data for Swindon CCG, 2013/14

Source: HSCIC QOF

**Treatment** – Early stage retinopathy may not need treatment, but more advanced retinopathy may require laser treatment or injections of medicine into the eye. Immediate treatment may not be necessary if it is: stage one (background) retinopathy, stage two (pre-proliferative) retinopathy or maculopathy with no symptoms. However, screening checks must still be attended to monitor the progress of the retinopathy. Advice on how to control diabetes will also be given. When treatment is necessary, laser treatment should be offered for proliferative (stage three or four) diabetic retinopathy and some cases of maculopathy.<sup>22</sup>

### 6.5 Other conditions that can affect eye health

**Uncorrected refractive error** – A refractive error is a very common eye disorder. It occurs when the eye cannot clearly focus the images from the outside world. The result of refractive errors is blurred vision, which is sometimes so severe that it causes visual impairment. The four most common refractive errors are:

- 1. Myopia (near-sightedness): difficulty in seeing distant objects clearly;
- 2. Hyperopia (farsightedness): difficulty in seeing close objects clearly;
- 3. Astigmatism: distorted vision resulting from an irregularly curved cornea, the clear covering of the eyeball.
- 4. Presbyopia: which leads to difficulty in reading or seeing at arm's length, it is linked to ageing and occurs almost universally.

Refractive errors cannot be prevented, but they can be diagnosed by an eye examination and treated with corrective glasses, contact lenses or refractive surgery. If corrected in time and by eye-care professionals, they do not impede the full development of good visual function. Correction is provided in different forms according to the defect, the age of the person, the requirements in terms of work of activity performed.<sup>23</sup> It is estimated one third of adults aged 40 and over are affected by uncorrected refractive error.<sup>31</sup>

**Stroke** – Stroke can sometimes damage the parts of the brain that receive, process and interpret information sent by the eyes. This can result in losing half of the field of vision – for example only being able to see the left or right hand side of what is in front of you. Strokes can also affect the control of the movement of the eye muscles. This can cause double vision. Up to two thirds of people experience some changes to their vision after stroke.<sup>24</sup> In Swindon in 2014 there are approximately 745 people living with a long standing health condition caused by a stroke.<sup>1</sup>

### 6.6 Inequalities

Local organisations identified a number of groups particularly vulnerable to sight loss in Swindon or where an increase in numbers is being observed. These include people with diabetes, people from black and ethnic minority communities (who are particularly vulnerable to diabetes related eye problems and glaucoma), people with learning disabilities, and older people with other co-morbidities. It was also highlighted that for people who have sight loss and another condition such as autism or dementia, the sight loss can both exacerbate the condition but also be misinterpreted as symptomatic of the condition. For example people may appear to have cognitive impairment which could be seen as an early sign of dementia, when their behaviour is actually due to an inability to see clearly.

Vision problems can be common among people with learning disabilities. Of the 1.5 million people in the UK who are known to have a learning disability, at least one in 10 has significant sight loss. This is particularly the case for people who are more profoundly disabled. Six in 10 people with learning disabilities need glasses and though this sight loss is less serious, they may not have glasses and/or the support to get used to them. Overall, the estimates suggest that in the UK today around 96,500 adults with learning disabilities (including 42,000 known to the statutory services) are blind or partially sighted. This may be the result of an organic and/or structural problem linked to the cause of the learning disability; the eye and the brain are very closely connected. Several conditions (such as

Down's Syndrome and cerebral palsy) are particularly likely to cause eye problems. Many people, particularly at that profounder end of the spectrum, have multiple disabilities in any case. However, the problem is also that sight problems from the correctable to the disabling are going unnoticed.<sup>25</sup> It is estimated 775 people in Swindon will have a learning disability, whilst only 548 are known to local social care services (2012).<sup>30</sup>

### 6.7 Additional disability

Table 15. Proportion of people registered blind or partially sighted that are recorded as having an additional disability in Swindon, Milton Keynes, South West and England, total up to March 2014.

Proportion of people registered blind or partially sighted with an additional disability46.0%40.6%24.3%34.7%		Swindon	Milton Keynes	South West	England
	registered blind or partially sighted with an additional	46.0%	40.6%	24.3%	34.7%

Source: HSCIC

# 7.0 Health determinants

The Government have identified the importance of ensuring that people do not lose their sight unnecessarily. The Public Health Outcomes Framework for England includes an indicator for the prevention of sight loss, and recognises the link between sight loss and wider determinants of health.<sup>26</sup>

### 7.1 Risk factors for developing sight conditions

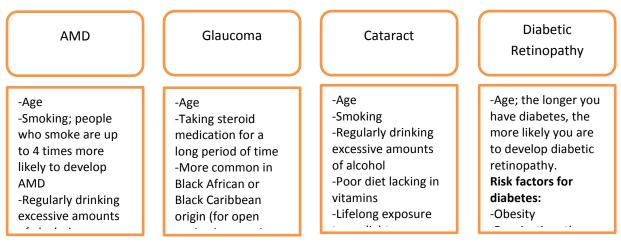


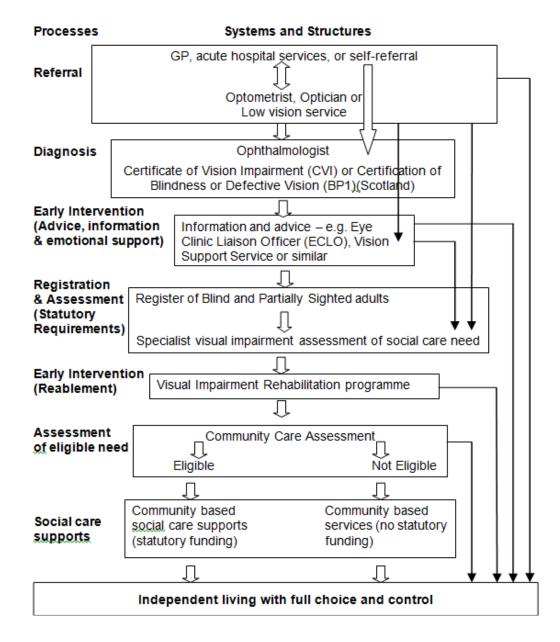
Figure 8. Risk factors for developing sight condition, by each main condition.

Part of an effective pathway for eye health is to ensure preventative and early intervention services are available.

## 8.0 Support, Activities and Service Provision

The provision of emotional and practical support at the right time can help people who are experiencing sight loss to retain their independence and access the support they need. Patient experience in the eye clinic is crucial. It is here that people receive their diagnosis, undergo treatment and potentially go through the process of receiving a Certificate of Vision Impairment. Equally, when someone experiences sight loss it is vital for them to have support in their homes and communities, including social care provided by local authorities.<sup>2</sup>

The best practice pathway for Eye Health is shown below<sup>34</sup>. This is a process map for the 'Seeing it My Way' outcomes framework.



#### Figure 9. Adult UK Sight Loss pathway.

Seeing It My Way sets out 10 outcomes identified as priorities by blind and partially sighted people:

- 1. That I understand my eye condition and the registration process
- 2. That I have someone to talk to
- 3. That I can look after myself, my health, my home and my family
- 4. That I receive statutory benefits and information and support that I need
- 5. That I can make the best use of the sight I have
- 6. That I can access information making the most of the advantages that technology brings
- 7. That I can get out and about
- 8. That I have the tools, skills and confidence to communicate
- 9. That I have equal access to education and life-long learning
- 10. That I can work and volunteer.

#### 8.1 NHS Sight Tests

People are eligible for an NHS sight test under a number of different criteria, for example aged 60+, aged 16 and under or in receipt of certain benefits. Recent published data on sight tests only highlights those paid by the NHS. Some eye tests are privately funded, and these are not included in this data. There were a total of 51,289 NHS sight tests in Swindon in 2012/13.<sup>9</sup>

	Swindon	Milton Keynes	South West	England
All ages	24,200	24,346	24,289	23,067
Aged 60+	88,741	42,033	38,433	45,410
Aged 15 and under	10,824	22,681	25,207	23,200

#### Table 16. Rates of sight tests per 100,000 population 2012/13

Source: HSCIC

Numbers of sight tests in 2013/14 are not available by local area, instead are available by NHS Area Team. An estimate for Swindon using the previous 3 years average represented in Table 17.<sup>29</sup> This may suggest the figures for 2012/13 in Swindon were an anomaly (Table 16).

#### Table 17. Estimated rate of sight tests per 100,000 population in Swindon in 2013/14.

	Rate of sight tests per
	100,000 population
All ages	24,398
Aged 60+	66,183
Aged 15 and under	19,123

Source: HSCIC

In the Health Survey for England 2013, 29% of women and 41% of men reported they did not have an eye test at least every 2 years, which is the minimum frequency recommended by RNIB. As age increased so did the frequency of sight tests. The reported frequency of eyesight tests decreased as equivalised household income decreased.<sup>27</sup>

Estimates suggest that nationally 69% of sight tests are NHS funded: in 2005/6 this was out of a total of 17.5million.<sup>37</sup> Applying this proportion to the estimated number of sight tests in 2013/14, it is estimated there were 23,902 privately funded sight tests in addition to the 54,220 NHS funded sight tests. Comparing this to the population, approximately 36% of the population had a sight test in 2013/14.

There are around 30 ophthalmic opticians in Swindon including both large companies such as Boots or Specsavers and independent providers.

### 8.2 Ophthalmology department

The Ophthalmology Department at Great Western Hospital (GWH) provides outpatient, elective and emergency eye services for the local population of Swindon and surrounding areas. Last year (2012/13), the department undertook 34,717 appointments, (9,998 new appointments and 24,719 follow up appointments) and performed 1,508 elective surgical cases in the same period.

The Ophthalmology Department had not been taking any new eye patients from Jan 2014 to Jan 2015 due to capacity issues although it has recently started admitting new patients again. Instead patients were being treated by other local providers and also outside the area. Other local providers include the Taw Hill Medical Practice (provided by Newmedica) and BMI Ridgeway in Wroughton. In Oct 2014, GWH opened a new eye clinic in Eldene Surgery for general eye clinics, as well as treatment for Glaucoma patients and an Oculoplastics service which offers operations involving the eye lids, socket or eye ball.<sup>28</sup>

GWH have also recently introduced an Eye Clinic Liaison Officer (ECLO) to work across the hospital.

### 8.3 Social care

In 2012/13, the RNIB Sight Loss Tool estimates there were 100 blind and partially sighted people in receipt of adult social care services paid for or provided by Swindon (Table 18). This data is gathered from National Adult Social Care Information Centre, Adult social care: Referrals, Assessments and Packages of Care data, 2012/13.

Table 18. Estimated numbers of social care recipients in Swindon, Milton Keynes, South
West and England, 2012/13

	Swindon	Milton Keynes	South West	England
Estimated number of blind and partially sighted people in receipt of adult social care	100	280	3,180	31,740
Estimated proportion of blind and partially sighted people in receipt of adult social care	18%	23.8%	10.6%	10.6%
Number of DLA claimants	200	280	5,550	61,750

Source: Sight Loss Tool

From the local authority records in July 2014 there were actually 30 adults (utilising 56 service packages) in receipt of social care packages who were recorded as being visually impaired. In February 2015 this had increased to 45 recorded as having a primary support reason of visual impairment or dual impairment, equating to 64 packages of care: 8 of whom are aged 18-64 and 37 are 65+. For both age groups the most common package is the Guide Communicator Service followed by domiciliary care and equipment.

Support services are commissioned by Swindon Borough Council from SEQOL who also then commission from Guide Dogs for the Blind, particularly for assessments for people who may be eligible for a guide dog. In addition Swindon Borough Council commission a dual sensory impairment guide communicator service so people can have someone to take them out every week to a place or to do an activity of their choice.

Up until August 2014 there was a dedicated rehabilitation officer but this post is no longer available. Concern was expressed by the voluntary sector and patients that although there are non-specialist staff supporting people with sight loss, the level of support is less than before. A particular gap identified was in-depth mobility and re-enablement training that could potentially keep people independent and give them more confidence.

### 8.4 Voluntary Sector

There are two main volunteer organisations in Swindon: Swindon Blind Association and Wiltshire Sight.

Swindon Blind Association offer a craft club on Tuesdays from 10am to 2pm, a social club on Wednesdays from 2pm to 4pm with visitors providing entertainment and talks and a resource room open once a month. The organisation also provides minibuses to bring members to the social club and organise ad hoc trips and visits. Around 18-20 people on average attend each session; most of whom are retired. Swindon Blind Association also provide small grants to purchase equipment. As a voluntary organisation it is primarily funded via donations. The organisation is open access but also get referrals from Taw Hill and Eldene Eye Clinics.

Swindon also has a talking newspaper service with 40+ volunteers and around 200 listeners who subscribe to a weekly USB stick of news and commentary. Swindon Borough Council meets the rent and utilities costs of the studio.

Wiltshire Sight operate across Swindon and Wiltshire providing a range of services including:

- Prevention and early intervention,
- Resource centre in Devizes,
- Advice desk at Great Western Hospital,
- Eye Can information days and workshops,
- Assistive technology,
- Zoom Club for children and young people
- Eye Chat for families and carers, and
- Sight loss awareness training.

Their primary source of funding is fundraising, charitable donations and small grants. The organisation have recently updated the guide to Sight Loss Services in Swindon and this is

available on their website, via GPs, Eldene library, Swindon Advice and Information Centre and other locations. In the last 12 months to end of January 2015 Wiltshire Sight supported 423 people in Swindon. These are people that have come to drop-ins, been given e-mail or telephone support, been individually supported in own home, or been on a 'Moving On' course (a morning session over 6 weeks, bring in agencies around different themes, e.g. independent vision to demonstrate equipment, living basics, emotional issues. Some of these have turned into peer support groups that are self-supporting).

Both organisations praised GPs for their awareness and support for people with sight loss. GPs have a toolkit for supporting people with sight loss.

Other services which cover Swindon include BATS which is a social club for active people with sight loss in Swindon. Activities include tenpin bowling, ice skating and theatre trips.

### 8.5 Equipment

One way to retain independence is via the use of specialist equipment. Discussions with the voluntary sector highlighted a number of useful devices which can support people including:

- Devices which can identify what colour clothing is
- A 'pen friend' that reads barcodes to say what the item is, e.g. can of beans, your clothes or CD's.
- Devices that scan, magnify and clarify documents, act as security devices and work as a mirror to do make up etc
- Scanners which scan documents and read the text out loud

### 8.6 Additional impacts of sight loss

Sight loss can have an impact on risk of injury. In Swindon in 2013, it is estimated that 665 falls occurred in people with a visual impairment. It is thought that 291 falls can be directly attributable to the visual impairment.<sup>3</sup>

Poor eyesight in drivers has also been highlighted locally as an issue by Wiltshire Police. Nationally there are no official estimates of the number of drivers and motorcyclists on the road with eyesight that fails to meet the minimum legal standards. However, some studies suggest 2% to 3% of drivers have vision below the minimum legal standards. Poor vision is only recorded as a contributory factor in less than 1% of reported road deaths and injuries, although this may be an under-estimate due to the difficulties in assessing whether poor eyesight played a role in accidents.

In 2011, 5,285 drivers and motorcyclists had their licences revoked because they could not pass a standard eye test, an increase of 8% since 2010<sup>32</sup>. This is a potential issue across age groups (older people in general tend to have less accidents than younger people). Wiltshire Police estimate 1 in 5 car accidents involve someone with eyesight problems. A national report commissioned by the insurer RSA recommends that all learner drivers should have their vision tested by a qualified professional prior to applying for a provisional driving licence. And that eye tests should be mandatory every 10 years, linked to driving licence renewal, with drivers encouraged to voluntarily have their eyes tested every two years in line with NHS recommendations<sup>33</sup>.

## 9.0 Recommendations

Sight loss can reduce people's resilience to the adverse effects of ill health and injury and also affect quality of life. It increases frailty and reduces levels of mobility. It is important that all stakeholders in Swindon support people to live life to the full and maintain independence as long as possible. This profile and recommendations will inform service redesign work and the development of an action plan to outline Swindon's implementation of the UK Vision Strategy.

The recommendations below are based on the information from the Sight Loss Profile. However it should be recognised that much information around sight loss is based on prevalence studies and hence estimated.

- 1. Investigate why Certificate of Visual Impairment rates in Swindon are lower than elsewhere and ensure that people are aware of the benefits of registration when they have their CVI assessment.
- 2. To increase the number of children accessing eye tests.
- 3. Take into account the projected increase in the number of older people with potential sight loss when planning services both in terms of type of condition that may need treatment and diagnosis but also the nature and accessibility of provision.
- 4. Recognise the likely increase in people with co-morbidities with sight loss including dementia, and the needs of people with dual sensory loss.
- 5. Increase awareness of existing provision and support and ensure appropriate information is available once diagnosed, from providers, via Swindon Advice and Information Centre, and via MyCareMySupport.
- 6. Ensure that effective and in-depth mobility and enablement support (e.g. using a white stick, software support) and training are available to people with sight loss in Swindon in line with good practice guidelines.
- 7. To increase the proportion of people with diabetes who attend diabetic retinopathy screening to equal or exceed the England average.
- 8. Raise awareness of the risk factors for sight loss conditions and prevention including lifestyle changes and regular sight tests.

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