Shaping the Future

Report on the review of the UK Vision Strategy and consultation on the future of work in eye health and sight loss

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Acknowledgements

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Acronyms

AV	Audiovisual
CVI	Certificate of Vision Impairment
CCEHC	Clinical Council for Eye Health Commissioning
CCG	Clinical Commissioning Group
ECLO	Eye Clinic Liaison Officer
EVS	England Vision Strategy
FYFV	Five Year Forward View
MLA	Member of the Legislative Assembly (Northern Ireland)
NHS	National Health Service
NIIP	Northern Ireland Implementation Plan
NCVO CES	National Council of Voluntary Organisations Charities Evaluation Services
PAG	Project Advisory Group
RNIB	Royal National Institute of Blind People
SVS	Scottish Vision Strategy
UKVS	UK Vision Strategy Team
UNCRC	United Nations Convention on the Rights of the Child
UNCRDP	United Nations Convention of the Rights of Persons with Disabilities
VSLG	Vision Strategy Leadership Group

Summary

The following is a five-page summary of the project report which includes the background to the project, our findings, conclusion and recommendations.

About the UK Vision Strategy

The UK Vision Strategy (the Strategy) is a cross-sector initiative seeking to unite everyone in the UK who wants to take action on issues relating to vision.

Created in 2008 and refreshed in 2013, the Strategy is led by the Vision Strategy Leadership Group (VSLG) which has representatives from across the eye health and sight loss sectors. There are country implementation plans for each of the four nations of the UK.

About the project and the data

'Shaping the future' is a review and consultation project to gather views on the extent to which progress has been made on the Strategy's outcomes and to gather ideas to shape the future of work in eye health and sight loss.

This project was carried out from June to December 2016 by an independent team from NCVO Charities Evaluation Services. We took a collaborative approach to this project involving a range of stakeholders in designing the work, inputting their views and co-producing recommendations.

A mix of qualitative and quantitative data was gathered via surveys, interviews, group discussions, workshops and events, engaging approximately 750 unique individuals.

This sample size is relatively small and does not allow us to generalise to the whole population. However we have been able to identify common themes in respondents' experiences and opinions, as well as to look in-depth at how and why progress has or has not been made, and to draw conclusions and make recommendations for the future.

Context

Our findings and recommendations are set against a backdrop of contextual factors, gleaned from our data and literature review, which are important to consider when shaping future work.

First, in relation to the operating environment for eye health and sight loss

services, there are three main issues: a decline in funding, an ageing population and increasing demand for services which is greater than current supply.

Second, cross-cutting themes include increasing devolution and localisation, the pros and cons of collaboration and the existence of a number of other frameworks, strategies and plans.

Progress towards the Strategy's three outcomes

Our data shows an overall perception that some progress has been made against all three outcomes of the Strategy but more needs to be done. Given the broad nature of the outcomes and in the absence of systematic monitoring and evaluation since its inception, it is not possible to state whether this progress can be attributed to the Strategy.

Around 40% of respondents to the professionals' survey perceived some progress to have been made on each of the three outcomes in the Strategy. However 42% said that they did not know whether the Strategy had contributed to these changes, 30% said it had played a minor role, 24% said it had played a major role and 4% said not at all.

In relation to **Outcome 1 (everyone looks after their eyes and their sight)** perceived achievements include:

- the Public Health Indicator for Eye Health in England [1] (referred to as the Public Health Indicator from now on)
- awareness-raising initiatives, such as National Eye Health Week [2]
- greater availability of eye tests in some areas and for some groups of people.

But more needs to be done to further raise awareness and to enable people to take better care of their eye health.

The perceived achievements of **Outcome 2 (timely treatment and appropriate support)** are that there have been some improvements to:

- early detection
- services and support when sight loss occurs
- cross-sector collaboration enabling a more joined-up pathway for some conditions, meaning more timely treatment.

More needs to be done to improve availability and accessibility of support, research on treatments and cures to help tackle currently unpreventable causes of sight loss, and move towards more seamless, person-centred treatment and support.

For **Outcome 3 (a society in which people with sight loss can fully participate)** perceived achievements include:

- improvements to transport
- technological developments
- more accessible information.

However more needs to be done to increase public understanding of the realities of living with sight loss. The public should be enabled to identify with people with sight loss more and to challenge discrimination. This should involve taking an asset-based view of people with sight loss, focusing on what they can do rather than what they cannot.

Learning for the future

Alongside the outcomes data five cross-cutting themes emerged that are important to consider when shaping any future work. Details of progress made and future considerations in each of these five thematic areas are provided below.

1. **Reduce service fragmentation.** The Strategy has fostered collaboration and given the eye health and sight loss sectors a more unified voice to governments. However more work could be done to reduce fragmentation across the eye health and sight loss pathway and increase collaboration, most notably in the voluntary sector.

2. **Involve people with sight loss more.** The Strategy has involved people with sight loss, including at design stage. This needs to continue and grow in the future including better engagement of people with sight loss in the leading of the Strategy.

3. **Consider the nature and role of the Strategy.** The three outcomes are comprehensive and the Strategy has enabled local groups to come together to take action. However further thought needs to be given to: the Strategy's role in achieving the outcomes; making the Strategy more actionable; better monitoring and evaluating; how to reach a wider audience; and leadership and governance of the Strategy.

4. **Consider the UK-wide remit.** The Strategy has helped improve collaboration at the country level, including with government, and devolved nations have been able to influence some aspects of government strategies.

What needs re-thinking is how to better resource in-country work and to what extent a UK-wide Vision Strategy is still relevant.

5. **Connect better with government.** There has been some government support for the Strategy particularly in the devolved nations. More could be done to gain more involvement at various levels of government; to respond better to government and health service priorities; and to connect with other sector initiatives more effectively.

Each of these issues play out to varying degrees in the four nations.

Recommendations

We recommend considering the following, some of which are about **what** future work could focus on and some are about **how** future work could be organised.

What future work could focus on:

- Increasing public awareness about eye health and taking care of sight.
- Lobbying for more research into treatment and cures.
- Understanding what barriers exist for people to access currently available support.
- Promoting an asset-based approach, encouraging people to look at what people with sight loss can do, rather than what they cannot.
- Reviewing the **Adult UK eye health and sight loss pathway [3]** and co-creating a theory of change with accompanying measures of success that can be regularly monitored, evaluated, shared and learned from.

How future work could be organised:

- Nature: should there be another strategy and if so consider how best to write, communicate, lead and implement it? If not what would the alternative be?
- Greater input and leadership by people with sight loss.
- Story telling: share people's stories of the realities of living with sight loss.
- Campaigns: run simple, public-facing, targeted campaigns.
- Collaboration: encourage organisations working in eye health and sight loss to work together.
- Influence local and central governments and the NHS, linking into their existing policies and agendas.

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- A devolved endeavour designed in-country with specific, relevant pursuits.
- Quality and self-assessment, for example, developing a national standard and templates of good practice with a catalogue of actual good practice that can be showcased.

Next steps

A final draft of this report was reflected on and discussed at the Vision Strategy Leadership Group meeting in December 2016.

The learning and recommendations in this report will be taken forward by a Vision Strategy Transition Programme. This Programme will seek a renewed agenda for change across the eye health and sight loss sectors, building on the ambition, experience and lessons learnt from the UK Vision Strategy. The Programme will work to agree the future priorities for collaborative work with cross-sector endorsement, and will establish channels for delivery.

1.   Introduction

1.1 About the project

The 'Shaping the Future' project is a six-month review and consultation project commissioned by the Royal National Institute of Blind People (RNIB) and steered by the Vision Strategy Leadership Group (VSLG). The purpose of the project is twofold: to gather learning about how well the refreshed **UK Vision Strategy 2013-2018 [4]** (the 'Strategy') has worked, and to consult on what future work in eye health and sight loss should focus on and how best to carry this out.

NCVO Charities Evaluation Services (NCVO CES) was commissioned to carry out this project starting in June 2016. The independent team took a mixed-methods approach to the research and was supported by the UK Vision Strategy (UKVS) team as well as a Project Advisory Group (PAG).

With the help of the UKVS team we communicated openly about each phase of the work through a dedicated website and provided our contact information so that people could access the independent project team directly.

1.2 About the UK Vision Strategy

The Strategy 'seeks a major transformation in the UK's eye health, eye care and sight loss services.' It aims to be a 'cross-sector initiative, uniting all those in the UK who want to take action on issues relating to vision.' **[5]**

The Strategy seeks to achieve three outcomes:

1. Everyone in the UK looks after their eyes and their sight.
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.
3. A society in which people with sight loss can fully participate.

Different implementation plans have been formed for the four countries of the UK to reflect different contexts and to turn the Strategy into reality.

Originally developed in 2008 by leading eye health and sight loss organisations across the UK, the Strategy was refreshed in 2013 and is intended to run until 2018.

1.3 About the review and consultation

Our approach

We were collaborative in two ways:

1. **In the design of the review and consultation, we:**
   - involved a PAG and the VSLG at meetings and through updates
   - provided opportunities for the PAG/VSLG to contribute, for example by asking for suggestions of people to interview, requesting comments on our approach and asking for feedback on our suggested data collection tools
   - requested that people with sight loss trial our surveys before they went live.

2. **In engaging stakeholders to give their views, we:**
   - invited organisations to canvass views from their colleagues by facilitating their own 'engagement events', for which we provided ideas in an online toolkit
   - invited a range of stakeholders to consider the findings and co-produce recommendations for our team to consider.

The data

Mixed-methods

We took a mixed-methods approach to gathering information as follows:

- A desk-based, rapid literature review to set the context around sight loss and eye health.
- Two online surveys:
  - a people's survey for people with, or at risk of, sight loss
  - a professionals' survey for anyone working within eye health or sight loss or with people with sight loss
- One-to-one interviews with 16 professionals working in eye health or sight loss **[6]**.
- Engagement events at which we facilitated discussion on an agreed list of questions.

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Response rates

We estimate we have heard from 750 unique individuals across approximately 140 organisations. This is an estimate because although we have a total count of 836 individual responses (315 respondents to the people's survey, 209 to the professionals' survey and 333 at the engagement events) we know 21 people completed both surveys but we are unsure how many people who completed a survey may also have given their views in an event.

Our people's survey sample broadly reflects the national data with regard to:

- sight loss profile: half our respondents said they were blind, the other half said they were partially sighted

- gender: we had a 66% to 33% split female to male which closely reflects national data which shows a 63% to 37% (female to male) split among people with sight loss

- ethnic makeup of the UK: most of our respondents described themselves as white (91%).

Our professionals' survey included a range of professions based on the 158 respondents of 209 who stated their profession. This includes: eye clinic liaison officers (ECLOs), those working in sight loss charities, optometrists, orthoptists and vision rehabilitation workers.

Further detail can be found in Appendix Two.

Issues to consider

Sample size

Our sample size is statistically small:

- There were 315 respondents to the people's survey, of which 211 were either blind or partially sighted [7]. By comparison there are 350,000 people across the UK registered as blind or partially sighted [8].

- There were 209 respondents to the professionals' survey. We do not have national data on the number of professionals working in sight loss and eye health across the UK but our sample is likely to represent a small percentage of them.

- Alongside stakeholders we collected a lot of qualitative data, involving approximately 340 individuals via 44 different meetings, discussions, events or one-to-one interviews, 21 of which were facilitated independently by NCVO CES. However this sample is still small relative to the total population.

In the qualitative data we may have only talked to a small number of people in a particular area or sector. So to maintain their anonymity, we often do not say exactly how many people expressed a particular view.

Geography

The majority of our data is from England: 78% in the people's survey and 74% in the professionals' survey. This limits what we can say about the UK-wide priorities and Strategy achievements.

Age and employment

We had a younger profile in our survey sample than the national average.

The employment status of our sample did not match the national average for people who are registered blind or partially sighted. There were fewer 'retired' respondents in our sample than would be expected. This ties in to the younger profile of the sample.

Professions

We had a range of different professions from across the eye health and sight loss sectors represented in our respondents to the professionals' survey. However, we are not able to compare this to national data to say whether or not this was representative of the full range of professions.

The engagement events provided some opportunity to hear from eye health professionals and the survey data is triangulated with the qualitative data from these events.

Attribution

While there is evidence of outcomes and impact it is hard to definitively attribute these to the Strategy for a number of reasons:

1. the number of other actors involved
2. the lack of ongoing monitoring and evaluation
3. the breadth of the outcomes sought by the Strategy
4. the lack of an underlying theory of change, identifying intermediate outcomes to be achieved along the way to the Strategy's three overall outcomes.

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1.4 About this report

The report contains the following sections:

- **Background** to the project outlining the environment for eye health and sight loss services and the context in which the Strategy has been operating.

- **Key findings** in which data is presented and analysed in relation to two areas:

    a. Cross-cutting themes that have emerged from the data such as collaboration, involving people with sight loss and devolution.

    b. Progress against each of the three Strategy outcomes.

- **Country stories** presents an analysis of the data (mainly qualitative) specific to Scotland, Wales, Northern Ireland and England.

- **Conclusion**.

- **Recommendations** including those that emerged from the co-production workshop (15 November 2016).

2. Background

2.1 The operating environment for eye health and sight loss services

Three broad issues were raised in the professionals' survey; we found echoes of these in our literature review. These are:

- decline in funding
- the ageing population
- demand for eye health and sight loss services being greater than supply.

Although it could be argued that these are contextual challenges for all services operating in the UK, they were raised as significant challenges for eye health and sight loss as detailed below.

Decline in funding

Eye health and sight loss services, like other services, will continue to be challenged financially.

NCVO's annual Almanac [9] shows that although income to the voluntary sector as a whole from government rose in this period, there has been a longer-term pattern of declining levels. NCVO found that grants had been halved over the previous ten years (at £2.8billion). In addition there is variation within the sector; 80% of the sector's total income goes to 3% of the total number of charities (just under 163,000).

The ageing population

The Office for National Statistics **[10]** predicts that by 2030 the number of people aged 65 and over will have risen by 50% and those aged 85 and over will have risen by 100%. Those aged over 65 will account for 22% of the population.

There are two million people with sight loss. Nearly 80% of these are aged 64 or over and those who are the 'oldest old' are at greatest risk – one in every three people aged 85 and over is living with sight loss.

By 2030 it is expected that 2.7 million people will be living with sight loss. This is driven by an increase in the number of people living longer as well as rising levels of age-related diseases and rising level of obesity and diabetes.

Deloitte Access Economics in the RNIB and Specsavers report **State of the**

Nation: Eye Health 2016 [11] estimated that the total costs (indirect and direct) of sight loss among the adult population to the UK economy was £28.1 billion in 2013. In 2008, the comparative cost was £22 billion, representing a significant increase over the last five years.

These statistics demonstrate the need to be prepared for an increase in sight loss and the pressure this will put on services and funding.

Demand vs supply

Given the ageing population and reduced funding there will be inevitable pressure on services such that supply is looking unlikely to be able to deal with increasing demand. This is already the case in some areas. For example some respondents in our data collection mentioned overcrowding in eye clinics.

2.2 The eye health sector

There are specific aspects of the eye health and sight loss sector that affect the Strategy. Discussing these will help to put into context the review of the Strategy and to consider its future and the future shape of work in these areas. These themes are:

- increasing devolution and localisation
- collaboration pros and cons
- other frameworks, strategies and plans.

Increasing devolution and localisation

The UK-wide trend of devolution and localised planning and spending is clear in health and social care. It looks different in each nation. For example clinical commissioning groups (CCGs) in England and territorial and national boards in Scotland, Wales and Northern Ireland.

New Philanthropy Capital's report **Boldness in Times of Change [12]** encourages engagement with the devolution model whether that involves understanding the different contexts and structures for national charities or working out who is best to engage with for smaller charities.

Collaboration pros and cons

The number of eye health and sight loss charities in the UK is estimated to be between 700 and 1200 (according to NCVO's UK Civil Society Almanac, **[9]** there were over 1200 organisations with eye health or sight loss listed in either their titles or their charitable objectives). The extent to which these charities work together or in silos is a subject for further exploration.

Across the UK there are a number of coalitions, umbrella bodies and infrastructure organisations all attempting to create change in the eye health/sight loss sector. For example:

- VISION 2020 UK – an umbrella organisation whose mission **[14]** is: 'to lead the collaboration of interested organisations in order to improve the eye health of the UK, prevent avoidable sight loss, and ensure inclusion and participation of people who have impaired vision in society.' It has strategic aims linked to this mission. Based on five key documents, **[15]** including the UK Vision Strategy, the priorities for 2016-17 are to:

    - promote collaborative working to effect change

    - deliver an Integrated Care Pathway

    - create a sustainable income model.

- Visionary **[16]** is a membership organisation for sight loss charities, societies and associations for blind and partially sighted people. It aims to develop and improve local charities and their services for blind and partially sighted people by connecting, influencing and developing its members.

- The Clinical Council for Eye Health Commissioning (CCEHC) which is made up of leading organisations. It was set up to be the 'national clinical voice for eye health in England' and to respond to government's NHS reforms for a clinically-led, patient-focused NHS **[17]**.

The Strategy has had various links with these organisations, but this needs to be carefully reviewed so that alliances can be built/renewed. There will be pros and cons to working collaboratively as some agendas may be shared where others may be different. Due consideration should also be given to the added value of having a Vision Strategy Leadership Group.

Other frameworks, strategies and plans

There are other frameworks, strategies and plans that cover similar issues to the Strategy.

Seeing it my way [18] is a set of ten outcomes that were identified through research with blind and partially sighted people in 2011. It asked them what was really important for them in being able to live independently. Seeing it my way was developed with support from the UKVS team and is branded with the UK Vision Strategy logo. Through the Seeing it my way toolkit, organisations in the sight loss sector can assess to what extent they are helping people to achieve these outcomes.

There are a variety of frameworks, strategies and plans in each of the nations, for example the **Wales Eye Care Delivery Plan [19]** and **See Hear [20]** in Scotland. These are explored further in the country stories (Section 4).

In England, the NHS' **Five Year Forward View (FYFV) [21]** sets out a new shared vision for the future of the NHS based around the new models of care. The FYFV is a business plan that aims to shift services to a community setting to reduce the pressure on hospitals, in addition to taking a more preventative, integrated approach to reduce some of the demands on the NHS. It includes a framework designed by the CCEHC for setting up local services in response to growing demand for ophthalmic services that cannot be met.

Sustainability and transformation plans are a recent development (from December 2015) setting out plans for the future of health and care services in the forty four new commissioning areas in England. Each plan describes how each area will implement the vision set out in the NHS FYFV. All forty four sustainability and transformation plans were published in December 2016. The Kings Fund recently published a report on how they are being developed in practice **[22]**.

The Public Health Indicator was, for the first time, included in the government's Public Health Framework in 2013. The minister who announced its creation referenced the Strategy as having influenced this.

The Indicator was developed in order to track changes in the numbers of people who are certified as sight impaired or severely sight from one of the three major causes of preventable sight loss: glaucoma, wet age-related macular degeneration and diabetic retinopathy

The VISION 2020 UK Ophthalmic Public Health Committee has developed a portfolio of indicators **[23]** in order to further track eye health, care and well-being at both a national and local level. It also allows inclusion of broader population indicators related to eye health to be tracked, such as levels of obesity, smoking and diabetes from the Public Health Outcomes Framework along with specific indicators from the NHS Outcomes Framework and the **Adult Social Care Framework [24]**.

The Adult Social Care Framework is about supporting people who need care and ensuring the care is of a high-level, delaying and reducing the need for care and improving the experience of care.

Finally there is the **CCEHC strategy 2016-18 [17].** As eye health was not explicit in the FYFV, the CCEHC has developed an integrated set of commissioning frameworks in response to growing demand for ophthalmic services. These include primary eye care services, community ophthalmology and low vision services.

CCEHC set out two strategic objectives:

1. To provide government, policy-makers, local eye health networks and commissioners with prompt, informed and evidence-based recommendations and be an effective partner on eye health commissioning matters.

2. To develop models of care and guidance to support commissioners and providers in (re)designing local services to address growing needs, capacity issues and to improve the quality and cost-effectiveness of patient-centred care.

The UK Vision Strategy has had links with some of these frameworks and plans. These links need to be reviewed and carefully considered so that alliances can be built/renewed and due consideration can be given to the necessity or not for continuing with the Strategy at all.

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3.   Key findings

This section presents our analysis of the quantitative and qualitative data from all our data sources.

Section 3.1 discusses respondents' views on progress towards each of the three outcomes and future work in each outcome area.

Section 3.2 is a discussion of cross-cutting themes that have emerged from the various data. These themes are worth considering when identifying what to focus on and how to organise future work in the eye health and sight loss sectors.

3.1 Progress towards the Strategy's three outcomes

The three outcomes are a helpful structure under which to review what progress has been made and what future work could focus on. It should be noted that due to the difficulties with monitoring and measurement mentioned in the introduction, progress towards each outcome cannot be directly attributed to the Strategy.

Outcome 1:
Everyone in the UK looks after their eyes and their sight

Summary

This section identifies three areas of achievement against this outcome: the Public Health Indicator; activities seeking to raise awareness of eye health; and some specific initiatives increasing the availability of eye tests. It also identifies two areas in which more could be done: raising further awareness of eye health and the need for eye tests and enabling people to take better care of their eye health.

What has been achieved

In our professionals' survey 39% (54 responses) stated that there had been some progress towards achieving Outcome 1.

The Public Health Indicator for Eye Health in England

The Public Health Indicator was seen as the key achievement under Outcome 1 by many respondents. This was achieved in 2012 prior to the refreshed Strategy.

Awareness raising initiatives

Professionals referred to key awareness raising initiatives as the next achievement for Outcome 1. They specifically mentioned: National Eye Health Week and

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the recent RNIB/Specsavers campaign. More generally they referred to greater publicity and encouragement for people to have eye tests for health reasons, not simply because they may need glasses. Respondents in the people's survey also mentioned that there were more TV adverts and campaigns to encourage people to look after their eyes.

Greater availability of eye tests

Some professionals also mentioned particular local initiatives such as mobile sight tests for those experiencing homelessness as an achievement under Outcome 1. Where free eye tests were available for all or part of the population, these were also seen as contributing to this outcome.

What more needs to be done

Raising further awareness of eye health and the need for eye tests

In our professionals' survey 64% (103 responses) stated that there had been gaps or disappointments in progress towards Outcome 1. Of those that provided a reason for their statement the majority stated that public awareness of eye health and the need for eye tests remains low. Some respondents stated that this was particularly true among vulnerable groups including some ethnic minority groups, those on low incomes, and those with learning disabilities.

Some respondents stated that the link to commercial optometry providers might be problematic:

"Most messaging with any profile about looking after your eyes come from commercially-driven advertising campaigns eg, Specsavers, which leaves a perception that it is all about selling you glasses, and less about looking after your eyes."

There was strong support for a coordinated public health campaign: respondents suggested a range of touch-points including schools, GP surgeries, workplaces, religious and community centres, care homes. Suggested channels included TV, leaflets, posters, social media and live events.

A few respondents suggested more TV coverage including a storyline in a popular soap opera. A total of 68 respondents (47%) referred to awareness raising in general, 29 of them suggested a co-ordinated campaign. Some respondents suggested targeting particular vulnerable groups.

Enabling people to take better care of their eye health

Some respondents to the professionals' survey pointed out that some 'avoidable' sight loss is unfortunately a result of people not following treatment regimes, such as injections or glaucoma eye drops. They also referred to a lack of awareness of preventative measures and lifestyle factors related to eye health. There may need to be more public education on these issues as well as better support for patients in the early stages of treatment to enable them to take better care of their eye health.

Outcome 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.

Summary

Three key areas of achievement were identified for this outcome: some improvements to early detection; some improvements to services and support when sight loss occurs; and the creation of a more joined-up eye health and sight loss pathway for some. Three areas for further work were also identified: improving the availability and accessibility of support; further research on treatments and cures; and continuing to work towards a seamless, person-centred pathway for treatment and support.

What has been achieved

Of the 141 respondents to the specific question about Outcome 2 in our professionals' survey, 38% (53 responses) stated that there had been some progress towards achieving Outcome 2. Respondents referred to a wide range of areas where some progress had been made.

Some improvements to early detection

A very small number of respondents mentioned that there had been some improvements to early detection, for example glaucoma screening by optometrists and a system for urgent referrals. The diabetic retinopathy screening programme was also mentioned as an improvement to early detection.

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Some improvement to services and support when sight loss occurs

The role of ECLOs was frequently mentioned by those who stated that some progress had been made towards Outcome 2. The increased number of ECLOs in hospital settings was also mentioned as a key achievement in many of the interviews and focus groups, and by some in the people's survey. Where ECLOs were present in hospitals and their role was well understood, smoother transitions from treatment to support were enabled. This depended on good communication between clinicians, ECLOs (where they existed) and those providing low vision services (whether in the social care or voluntary sector).

In the focus groups, some professionals in social care and the voluntary sector, for example vision rehabilitation workers, stated that they were seeing people at an earlier stage before their sight was completely lost and were therefore more able to support them to make better use of their residual vision:

"We find in the Adult Services team that more people are retaining some residual vision because of treatment and less time to wait, therefore our work as ROVIs [rehabilitation officers for visually impaired people] is about teaching use of the residual vision, [there are] less totally blind people coming through [our service]."

A more joined-up pathway for some

A very small number of professionals mentioned the Adult UK eye health and sight loss pathway and specific pathways and guidelines for particular conditions, in particular wet age-related macular degeneration. Those professionals said these pathways had enabled more timely treatment and reduced waiting times for these conditions, with the caveat that this might have a negative impact on those with other conditions who may have to wait longer.

Greater awareness among ophthalmologists of services and support for those with sight loss was also seen as a positive achievement. One survey respondent attributed this directly to the UKVS:

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"By working together on projects under the auspices of the UKVS, ophthalmologists are more aware of the importance of certification and the benefits of registration."

Where respondents stated that progress had been made on creating a more seamless eye health and sight loss pathway, they tended to also state that this was a result of greater collaboration between the health, social care and voluntary sectors.

What more needs to be done

Improve availability and accessibility of support

Across our survey respondents, regardless of age, employment status, level of sight loss and age at which sight loss occurred, three of the top four priorities were:

- more practical support to help people with sight loss to live independently (51% selected this as one of their top three)

- more information about help available and where to go (49%)

- more emotional support to help people come to terms with their sight loss (40%).

This suggests that these priorities need to remain a focus for the future. Two dimensions of this issue are explored below: access to support and amount and quality of support.

Access to support

Among professionals, there was an awareness that many people with sight loss were 'invisible' to the system, and may not be receiving any support at all, particularly from the voluntary sector:

"We held an event recently where we talked about partnership working – [we] frightened them by showing the gap between numbers of people with sight loss and those being served by charities. How can they help each other to do more?"

Some people with sight loss may also still 'fall through the cracks' especially at the point of certification or when transition takes place from hospital-based treatment to support from social care or the voluntary sector. This can sometimes be due to delays in registration, as one respondent explained:

"For example someone received a [Certificate of Vision Impairment] CVI with the signature of the consultant dated 2013 [but not issued until] two months ago [July 2016]. Someone had been living with sight loss for three years, knocking on everyone's door to get into the system."

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Accessibility of support was also an issue for respondents to the people's survey. 'More information about help available and where to go' was selected as the top priority (out of 10) by 25% of the people with sight loss who completed our survey (n=238). Over half of all survey respondents who had sought support for their sight loss (n=182) found it difficult to access the right support **[25]**.

The number of national and local sight loss charities and the different services provided by them and by statutory bodies can be confusing for some. Various suggestions were made for making it easier to find appropriate support:

"I think it would be useful to have a tagged digital 'library' or directory of what services for people with sight loss exist. These could be grouped in different ways. By type of service (eg Helplines, which are run by various groups such as RNIB and Macular Society) and by area. This could be a resource that all organisations working in the sight loss sector are automatic members of and that is maintained well. A bit like Homeless Link in the homelessness sector **[26]** but more thorough, so that people from any organisation – whether Moorfields or a local Blind Society – could run searches for specific services available."

"The creation of shared service centres/hubs in communities that provides information, outpatient services and opportunities for people with sight loss."

"You should have a single point of contact, it doesn't matter where they come from as long as they are able to facilitate all the necessary services for someone facing sight loss."

Amount and quality of support

For others, the support they received has been variable. For example, mobility training was in some cases extensive and in others almost cursory. In addition, some of the people with sight loss who responded to our survey talked about receiving support years after they were diagnosed. For those whose sight loss is stable there remains a need to keep up to date, for example with new technologies, and they are at risk of missing out on new information. These gaps or missed opportunities may mean that people are unable to live as independently as they can or would wish to.

Respondents to the people's and the professionals' survey as well as interview and focus group respondents suggested that having more ECLOs and ensuring that their role is well understood by clinicians would enable more effective support for those newly diagnosed. However, some respondents were concerned that the funding for this is limited and there is limited buy-in from senior figures in the NHS

to make funding available for ECLOs. Some professionals also mentioned cuts to funding for rehabilitation and the negative impact that this had on the availability of timely and appropriate support.

Further research on treatments and cures

Currently under 1% of the total medical research budget is spent on eye health research **[27]**. However, with NHS capacity being stretched to the limit combined with an ageing population, a small number of respondents stated that the most effective course of action would be to find a cure for what is currently seen as unpreventable sight loss:

"We will never solve the capacity problem if we simply accept that more and more people will go blind. We have got to start tackling the unpreventable causes of sight loss and not simply focus on the little bit of difference we can make around the edges for people who have preventable issues. We can try and solve these but the long-term solution is to cure these problems."

Continue to work towards a seamless, person-centred pathway for timely treatment and support

While some respondents acknowledged that progress has been made towards a more seamless eye health and sight loss pathway others suggested that more still needed to be done. Two fifths (40%) of those who stated that little progress had been made referred to the inability of the NHS to cope with demand for treatment. This has led to longer waiting times in some cases, particularly for follow-up appointments. It has also resulted in shorter appointments with consultants in some cases, with less time for in-depth assessment and dialogue.

A key element of improving timely treatment and support was reducing fragmentation within the health sector and across the health, social care and voluntary sectors, as previously mentioned. There was considerable disagreement among health professionals as to whether certain services should be delivered in the community. Some professionals suggested that referrals could also be made at an earlier stage in the eye health and sight loss pathway rather than at the end of treatment:

"I constantly hear stories of virtual abandonment once the situation moves beyond the health professionals. In fact the situation is pretty dire in my opinion and has worsened considerably in recent years."

"[The] link between hospital and social services needs to happen; there's an assumption that one ends and the other one starts when actually people need to be referred much sooner before sight loss has become more severe."

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Outcome 3: A society in which people with sight loss can fully participate

Summary

Three key areas of achievement were identified for this outcome: improvements to transport in some areas; improvements in technology; and more accessible information. There were two areas in which further work was needed: promoting an asset-based view of people with sight loss and greater public understanding of the realities of living with sight loss.

What has been achieved

Of those who responded to the question about progress towards Outcome 3 in our professionals' survey (134 people), 38% stated that some progress had been made.

Improvements to transport in some areas

Respondents in both the people's and the professionals' survey, as well as some focus group respondents, said that improvements to transport, in particular talking buses on some routes, had made a positive difference to the ability of people with sight loss to fully participate. However, many respondents acknowledged that there was more to be done in making transport and the built environment fully accessible. Suggestions included increasing the number of talking buses on rural routes, reducing 'shared space' initiatives and removing street furniture.

Improvements in technology

Respondents in both the people's and the professionals' survey stated that improvements in technology, from low vision aids to talking cashpoints to computers and smartphones, had helped people with sight loss to participate more fully in society:

"I think this is an area that has seen improvement since the launch of the Vision Strategy. Technology is improving and this can have a significant impact on the independence and participation of visually impaired people in the broader society."

Again, respondents acknowledged that there was more to be done in terms of making technology fully accessible 'out of the box' and in making sure that people were able to use computers and smartphones and to keep up to date with new technologies.

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Accessible information

A small number of respondents specifically referred to the **Accessible Information Standard [28]** as an indicator of progress towards Outcome 3. This came into effect in July 2016.

What more needs to be done

An asset-based view of people with sight loss

Both people with sight loss and professionals working with those with sight loss called for an asset-based rather than deficit-based view of people with sight loss:

"People tend to see what you can't do, as opposed to what you can do. They look at the black and white areas instead of the grey. This goes for those with sight loss as well as those without, such as prospective employers."

Respondents saw this asset-based approach as key to changing attitudes towards people with sight loss:

"Changing attitudes is very hard and I feel little progress is made. I would like to see more people with sight loss taking a prominent part in public life, whether in business, politics or entertainment, to drive home the message that losing your sight is not the end of everything, and people with sight loss can still contribute to society. A visually impaired person regularly portrayed in a positive manner on a high-profile national TV program, factual or fiction, would be worth a hundred campaigns in influencing how the public views sight loss."

Some people with sight loss and professionals suggested that some sight loss charities continued to have a deficit-based view of people with sight loss and encouraged dependency:

"Helping the public image - some adverts put out by big charities are not helping the public image of people with sight loss, don't need pity adverts 'can't do this' as this will filter through i.e. to employers. Need to focus on other aspects of sight loss. National charities have to take responsibility as that is who the general public would have heard of."

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"Many local societies still have a 'traditional' approach which nurtures too much dependence, rather than encourage independence. Equally there are some trailblazing examples of innovation that delivers great programmes fostering participation, e.g. mobility, sports and activities, technology."

This asset-based view of people with sight loss also links to enabling people with sight loss to be more involved in the Strategy and in campaigning and supporting others, as previously mentioned:

"All organisations should actively involve blind and partially sighted people in these campaigns and be bolder in telling us that things won't change if we don't put ourselves out and campaign."

Greater public understanding of the realities of living with sight loss

Both those with sight loss and professionals working in the sector referred to an ongoing need to educate the public and professionals about the realities of living with sight loss. The people with sight loss who responded to our survey rated this as the third highest priority (out of 10) with 45% including it as one of their top three priorities. Nearly 30% of those professionals who responded to our question about what more could be done to achieve Outcome 3 also referred to greater understanding of the realities of living with sight loss – the most popular answer to this question.

Some respondents stated that raising awareness was the key to tackling a range of more practical issues including discrimination, transport and employment.

Some respondents suggested that there was a lack of emotional engagement among the public compared to other conditions such as cancer:

"Everyone knows someone who has had cancer, but people don't think of sight loss in the same kind of way. It is around them but it doesn't resonate."

Others referred to everyday examples of discrimination, including taxis refusing to take people with guide dogs, as well as ignorance from the general public:

"Sometimes if people see someone with a white cane they freeze or try and run across the road in front of you."

"More public information about how sight loss can vary so that people do not make the assumption you are not really blind/partially sighted. I find people can be rude and/or unhelpful and have even stopped in front of me to see if I can see them. This can knock my confidence in an already difficult world."

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3.2 Emerging themes

In addition to the data on progress towards the Strategy's outcomes, there were several other important cross-cutting themes that emerged.

These themes are not specific to any one of the Strategy's three outcomes but have affected (both positively and negatively) the achievement of all of the outcomes. They are important to consider when deciding the shape of future work.

These themes are described in this section. They are:

- bringing people together across the sectors
- involving people with sight loss
- the nature of the Strategy
- devolution
- high-level buy-in.

Bringing people together across the sectors

Summary

This section identifies two key achievements: that there has been more collaboration across the eye health and sight loss sectors and that the Strategy has given the sectors a unified voice to governments. It also identifies two key areas in which more work could be done: reducing fragmentation across the eye health and sight loss pathway and increasing collaboration within the voluntary sector.

What has been achieved

More collaboration

Many of our respondents, particularly those who had been more closely involved with the Strategy, stated that a key achievement of the Strategy was that it brought people together who might not previously have worked together or engaged meaningfully with each other. Respondents commented that voluntary sector organisations who may previously have been at odds with each other were working together more effectively. They also commended the way in which the Strategy had brought together those from across the whole eye health and sight loss pathway, from the health, social care and voluntary sectors:

"It has set out the entire pathway - from early detection right through to living with sight loss. It enables people to see their place in the pathway and how they relate to people on either side."

Conferences and events facilitated by the Strategy were highlighted as useful opportunities for these conversations to begin and for sharing information and developing collaborations:

"The conference works well for networking and partnership working and with non-charity partners."

Once the conversations had been started by the Strategy, many people talked about how they had gone on to develop joint working because of the way the Strategy provided a shared vision or at least a focus for their efforts:

"The Strategy has provided an important rallying point and focus for effort for the whole eye health and [visual impairment] VI sector for the first time in our shared and sometimes chequered history."

Unified voice to governments

Some respondents who had been involved with the Strategy at a senior level felt that this greater collaboration had enabled the sight loss sector to have greater influence with governments:

"Other disability groups come individually with a plethora of often conflicting demands whereas sight loss comes as one group. Undoubtedly it's been beneficial at that level of operation to have a single voice."

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What more could be done

Reducing fragmentation across the eye health and sight loss pathway

There were many calls among professional respondents for better joint working across the health, social care and voluntary sectors, with shared care pathways and shared information. This was linked to calls for a more person-centred approach to care:

"Stop primary, secondary, social and community care operating in silos treating a patient as a piece of commodity that lands at their door and then moved onto the next."

In general there was a sense that more could be done to break down barriers between clinical professions and across sectors including exploring opportunities for shared care or more extensive use of nurses and allied health professionals. Some respondents gave examples of successful models of delivery of eye health services in community care settings, for example, nurse-led glaucoma clinics.

In the professionals' survey 20% of respondents stated that reducing fragmentation both within the eye health and sight loss sectors and across them was important in order to meet the challenges facing both sectors. Some respondents stated that better information sharing was key to this, to avoid duplication and unnecessary repeat referrals.

Fragmentation and lack of collaboration was as evident in the eye health sector as in the social care and voluntary sectors. There was some disagreement among respondents as to which professions were best placed to deliver certain services. Some focus group respondents from the eye health sector highlighted ongoing competition between primary and secondary care, perhaps exacerbated by a climate of austerity.

Despite a high number of calls for greater integration, the Adult UK eye health and sight loss pathway and the Seeing it my way outcomes were rarely mentioned by professionals in our survey [29]. These have both been key efforts to reduce fragmentation across the eye health and sight loss pathway. This may suggest that more needs to be done to communicate and/or implement these initiatives.

Greater collaboration in the voluntary sector

There was also a view from some that the voluntary sector needs to collaborate more in order to achieve better outcomes for more people. In our professionals' survey 16% of respondents stated that this was an important way to meet the challenges facing the sector.

While the Strategy has been a good starting point for this, many professionals within the voluntary sector felt that inter-organisational relationships remained a barrier to effective joint working.

This was partly seen as an issue of personalities but also more widely an issue of 'organisational territorialism', the result being that some organisations were unwilling to 'share sovereignty':

"Often organisations are fighting for the same audiences, the same funding. That's a reality; charities are just as competitive as the private sector."

The fragmentation and duplication in the voluntary sector was also problematic for people with sight loss in that some found it confusing and difficult to access the right support.

Respondents highlighted both national and local aspects to improving collaboration. On a national scale, some suggested reviewing the role of larger charities and umbrella bodies to reduce duplication. Locally, the relationships of local to national charities could also be reviewed to empower local charities to deliver services more effectively, and not in competition with national bodies. 'Pooling resources', low-cost professional development and strategic planning expertise were suggested as possible ways to support local charities.

Involving people with sight loss in the Strategy

Summary

In this section we explore three key achievements: that the Strategy was originally developed by consulting people from the 'ground up'; that Outcome 3 supports people with sight loss' inclusion in society; and that some members of the Strategy's internal groups have sight loss. It also identifies the key to future improvement in this area is to better engage people with sight loss to lead the Strategy.

What has been achieved

Developed from the 'ground up'

The initial Strategy was developed through extensive consultation with over 650 individuals including those with sight loss, and many respondents stated that it represented the views and needs of all stakeholders well:

"[The] original one was done by this very big consultation. They came from listening to people – a big strength of the Strategy when talking to any governments. [It] wasn't from the top, [it] listened to real people."

Supports the inclusion of people with sight loss in society

Some respondents said that the original Strategy (developed in 2008) had been more eye health focused but the post-2013 revised Strategy had a more balanced focus, placing more emphasis than previously on people with sight loss being able to participate fully in society.

Groups shaping the Strategy have members with sight loss

People with sight loss are involved in the central UKVS team and on the various consultative bodies that we spoke to during the data collection phase.

What more could be done

People with sight loss more engaged and leading the Strategy

It was mentioned several times, particularly in interviews and focus groups, that people with sight loss could be more involved in shaping and leading the work of the Strategy. People at risk of sight loss had inevitably been even less involved because they are more difficult to reach.

"I would like to see a forum for representatives of each organisation and a broad selection of individuals with sight loss which works on this together."

Awareness of the Strategy is relatively low among people with sight loss. Of those with sight loss who responded to our people's survey:

- 55% (122 people) had not heard of the Strategy or the country implementation plans
- 39% (86 people) had heard of the Strategy
- 6% were not sure.

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It should be noted that our survey respondents were predominantly those in direct contact with sight loss charities such as RNIB and therefore could be expected to be more engaged than the general population of those with sight loss.

There was an appetite from those in leadership roles to involve people with sight loss more effectively at leadership levels:

"[Lay people with sight loss] don't sit on the Leadership Group, they have very little participation in VISION 2020. Now I say this to you it's really quite embarrassing. But that's not desirable and it's not sustainable, it's not credible."

"We should be led by people with sight loss who should hold us accountable."

"Encourage our members to speak up, have a voice, be engaged. If it is just us talking that's not enough. If they speak to local councillors, politicians etc we will have more of an impact."

In addition, some people expressed an appetite for more guidance as to how they could be involved in promoting the Strategy, for example, as ambassadors, in the model of Dementia Friends **[30]**.

The nature of the Strategy

Summary

This section identifies two key achievements in this area: that the three outcomes are comprehensive and that the Strategy has enabled local groups to come together and provided a structure through which to take action. It also identifies six areas that need to be re-thought: the organisational status of the Strategy; greater clarity of its role; making the Strategy more actionable; better monitoring and evaluation of the Strategy; how to reach a wider audience; and its leadership and governance.

What has been achieved

The three outcomes are comprehensive

The three outcomes were seen as acceptable to all those working in the eye health and sight loss sectors, regardless of organisation or specialism. Some organisations chose to set their own organisation's strategy, or to design projects or develop funding bids, in light of the Strategy, and those that had done so believed this to have been helpful:

"The aims are very broad and have very wide scope, making it easy to implement into a wide number of projects."

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Local groups have come together and taken action

The Strategy has also been a starting point for local Vision Strategy groups at various locations around the UK at different points in time. Those who had been involved in such groups whom we spoke to had found them extremely positive and were empowered to make changes in their local area, for example setting up local peer support groups or modifying the CVI process. Having the Strategy as a framework enabled these local groups to 'align problem definition' and explore the ways in which problems could be tackled as part of the existing work of various stakeholders.

What needs to be re-thought

The organisational status of the Strategy

Many respondents either expressed or referred to a certain degree of confusion as to both what the Strategy was and also how it worked organisationally.

In particular, respondents expressed or referred to confusion about the distinct roles and priorities of the UK Vision Strategy and VISION 2020 UK and their respective teams, and suggested that having two bodies with potential overlap and duplication was at best confusing and at worst inhibiting the progress of the Strategy.

Several respondents felt that there was a need for 'a single umbrella body' and that any future work could be more effectively delivered by joining resources particularly with VISION 2020 UK. This was linked to improving the clarity and transparency of its governance with many people saying that it must be independent to be successful:

"I tend to think that under VISION 2020 is the logical place for it to be. If it was there, rather than being driven by one organisation, people would be more likely to sign up to it if they thought it was common property, rather than that of one organisation."

It was also unclear to some people how the Strategy and the UKVS team related to the various organisations that already exist across the sectors. Some suggested that this may be to do with the way that the UKVS team is funded leading it to be perceived as an RNIB initiative and alienating some stakeholders:

"There is tension as the UK Vision Strategy [team] is paid by RNIB … It's messy and looks bad to [the] outside world. It creates uncertainty and lack of direction and needs one point of contact."

Clarity on the role of the Strategy

"People forget the Strategy isn't an organisation....it's a Strategy.... a document…"

Particularly in the interviews and focus groups, there was some confusion as to the nature and role of the Strategy, with respondents raising a number of questions. Is it an organisation or just a document? What authority does it have? How does it relate to the work that sight loss charities or professional bodies are already doing? Can, or should, it deliver anything directly? Who is accountable for making progress towards the Strategy's outcomes and what role does the UKVS team have in enforcing that accountability?

"If people don't do it – who's going to push them to? The Strategy lacks enforcement, nobody is held accountable."

"[The] hardest part of implementing some of the actions was it was already some of their work and what they should have been doing anyway."

"The UK Vision Strategy [team] behaves as an organisation, it doesn't have authority to implement anything."

Some respondents questioned whether the Strategy was really a strategy or more of a statement of aspirations. The lack of goals, timescales, baseline data or key performance indicators made it difficult to claim that it was legitimately a strategy and indeed to take meaningful action:

"The UK Vision Strategy is not a strategy. It is a document that articulates a series of aspirations. It makes no attempt to define the 'how' only the 'what'. It is so wide as to be unable to measure its impact." **[31]**

Making the strategy actionable

There were a number of suggestions of ways to make the Strategy more actionable.

Respondents stated that the breadth and vagueness of the three outcomes made it very difficult to measure progress:

"Because it is relatively vague, that people can sign up but not actually do anything."

Instead, it was suggested by some that priorities should be identified, and it was acknowledged that this is an approach being trialled in England:

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"We need to have one focus and say 'this is really important'. If you look at the strategy at the moment it tries to be all things to all people."

Alongside having this narrower focus, it was suggested by some people that it would be helpful to also have actions arising from the Strategy broken down step-by-step, with timeframes attached, with priorities identified from an evidence base:

"Maybe we need more iterations of the action plan so that you set something, measuring where you're getting to and working on it, and then finding out are we getting there, do we need to go out and find out from people, it's the process that we need to change."

"Broad Strategy with realistic projects that sit below it. Projects chosen for biggest benefit vs cost."

To implement this approach, some suggested having more tightly defined delivery mechanisms or groups, for example 'task and finish groups', so that people were clearer on how they could play their specific part in implementation. Some respondents suggested that having more focused tasks would increase momentum:

"I believe we need to stop and consolidate so that the purpose of the strategy is clear and that people understand their role in it."

"Which organisations are leading on specific priorities?"

"Form a group of people together from different places to do a particular thing. And when they've completed the task they wind themselves up and go and do other things."

Monitoring and evaluation

The interview and focus group respondents frequently referred to the lack of a monitoring and evaluation framework or any baseline data, which led to enormous difficulty in stating whether the Strategy had made any progress towards its aims, or to attribute any such progress to the Strategy. It was difficult to know whether any change would have happened anyway, due to the lack of focused actions and indicators:

"[I] don't think the UKVS [Strategy] has any real targets. Don't know what success is. That is the single biggest issue. Even if just for avoidable sight loss, I see no numbers, no targets.

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"Without strategic targets and robust baseline data to monitor progress against, there is currently no way of knowing whether ophthalmic public health, NHS and social care outcomes are better or worse than they would have been without the Strategy or whether the UK is closer to achieving the **VISION 2020 global goals [32]**, than it otherwise would have been."

A monitoring and evaluation framework was initially established but not used due to poor uptake and lack of staff time and resource to implement it. As a result, although there has been reporting of achievements, this reporting has not been useful for the purposes of reflecting on and improving the work of the Strategy, with reporting seen by some as a 'tick box exercise'. Others felt it had not focused on capturing the experiences of the Strategy's intended beneficiaries:

"We don't give time or much effort into collecting case studies which I think would be very interesting – the real experiences of real people."

Some respondents felt that a more open 'learning and sharing approach' would mean that future work would be more reflective and evidence-based in its approach and there would be a better understanding of 'the ingredients needed for change to happen':

"The crucial thing is that people should feel comfortable with being able to reflect on the way things are going to be and able to make changes without feeling that it reflects badly on them. We don't always get it right first time many of us."

Reaching a wider audience

There were suggestions that the Strategy largely involved the 'usual suspects from across the sectors' and that any future work needs to reach out to new audiences:

"We all know each other from the sector for years now, perhaps that's just a bit tired. [We] probably have similar discussions at every meeting. Perhaps we need to change or increase the pool on this board, so different areas or sectors."

The lack of outreach was partly seen as being an issue with language. As well as making the Strategy document shorter and more accessible, the word 'strategy' itself was perceived as only speaking to organisations, not individuals:

"The word strategy – people wouldn't understand what does it mean, how can we use it etc. Service users aren't interested in organisational strategy. Why do they need it?"

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"The new strategy needs to be shorter and written in plain English, broken down in to areas and could be called a 'declaration'. It could then be a tool suitable for blind and partially sighted people."

Some suggested that future work should be more outwards-facing and 'shout a bit louder', encouraging engagement with beneficiaries, people at the 'operational level' and people in other sectors, as opposed to just a relatively small group of senior professionals in the eye health and sight loss sectors:

"We need to create a popular movement!"

Leadership and governance

In sectors where there are many different stakeholders, each with competing priorities, leadership and governance of the Strategy remains challenging. Some respondents wanted to see 'strong leadership with clear identity' with some suggesting a national eye health lead or clinical director or CEO:

"There are so many stakeholders who have to be willing to play ball. Nobody has all the cards. No one is able to say 'Ok, let's do this'. There are too many players. There is no one to bang heads together."

However, given the range of stakeholders, some respondents also felt that it was important to be collaborative and to ensure that all stakeholders had a voice, while also getting things done:

"It's a rather curious thing of trying to find a way through, of having a member organisation, so people feel they belong and are being listened to, but actually of having a governance structure that makes sure you can get things done."

Some respondents also raised challenges with governance, in particular the Vision Strategy Leadership Group:

"Meetings with 25 people in them are effectively talk shops. You really have to be incredibly disciplined to get anything out of a meeting of that size which results in actions. And it's very hard to report back to a meeting of that size about what you've been doing and to be held accountable for it."

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The UK Vision Strategy in the context of devolution

This section explores the key shared themes from working in a devolved context that emerged from the data collected from Scotland, Wales and Northern Ireland. There were also many more distinct findings for each of these three nations; these are further detailed in Section 4.

Summary

This section identifies two key achievements: that the Strategy has helped improve collaboration at the country level, including with government, and that devolved nations have been able to influence some aspects of government strategies. It also identifies two key aspects that need re-thinking: considering how to better resource in-country work and to what extent a UK-wide Vision Strategy is still relevant.

What has been achieved

Collaboration, including with governments

Much like in the UK-wide findings, collaboration was felt to be one of the key achievements of the Strategy in Scotland, Wales and Northern Ireland. The Strategy was seen as a useful focus to share information, open up discussions and organise joined up working across the voluntary, public and private sectors.

What was distinct about this collaboration, compared to the English or UK-wide context, was the degree to which devolved administrations had been involved. Many stakeholders talked about their government's willingness to engage with the Strategy and there were often more government stakeholders on their country leadership groups. One respondent said:

"We are very lucky to have the Welsh government sitting at the table with us."

Influencing government strategies

Devolved nation stakeholders felt that government engagement had, in some cases, meant they had been able to influence government strategies. This was most commonly where the group had been consulted on the development of a new programme, for example, in the case of the Eye Care Delivery Plan for Wales, or where their knowledge of the Strategy was felt to have increased awareness of sight loss issues more widely across government, as in the case of Northern Ireland.

What needs to be re-thought

Resourcing country strategies

The devolved nation stakeholders felt that a lack of resources had sometimes been a barrier to them progressing implementation and achieving the Strategy's outcomes. It also meant it had sometimes been a struggle for country stakeholders to fulfil the reporting requirements to the UK Vision Strategy team.

They felt that with more resource, whether that was staff time or funding for projects, they would be able to more proactively build support for the Strategy, drive forward its implementation and track its progress.

"We can't have a Strategy that affects 5.5 million people and influences the Scottish Government and wider society and not put a penny into it."

Questioning a UK-wide Vision Strategy

Some respondents felt that the country structure had meant they had been able to tailor their work and approach depending on their country context. They felt this had helped them to achieve this engagement and influence.

Some took this further and questioned whether a UK-wide Strategy was the most effective approach, especially when most of the policy areas relating to the Strategy are devolved. They felt a wholly country-specific Strategy and approach would be likely to get better buy-in and better address local needs:

"If we were going back to the Northern Ireland plan we might be able to identify things that were particularly problematic for visually impaired people in Northern Ireland and I think there ought to be a Strategy for that in its own right … If we had carte blanche it might change the way we approach this."

High-level buy-in

This section identifies one key achievement in this area: that there had been some government support for the Strategy, particularly in the devolved nations. It also identifies three key areas in which more could be done: gaining more involvement at various levels of government; responding better to government and health service priorities; and connecting with other sectors' initiatives more effectively.

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What has been achieved

Some government support for the Strategy

Particularly in Wales, Northern Ireland and Scotland there were examples of government support for the Strategy, for example, through being part of their country's group or through working collaboratively with the voluntary sector in developing policy. In many cases the Strategy had provided the structure or vehicle through which to facilitate discussion with government, although some felt this had been 'more on the operational rather than strategic level'.

In England, the creation of the Public Health Indicator was also widely credited as being influenced by the Strategy. Some people also spoke about government doors now being 'more open'.

As previously stated, the Strategy had facilitated the sector's ability to speak with one voice to government and some respondents in interviews and focus groups saw this as a key factor in the sector's ability to influence national and local government.

What more could be done

More engagement at various levels of government

Some people felt that future work needed to engage at the political level more, particularly at the country level (Scotland, Northern Ireland and Wales) or the local level (within England). Gaining high-level political buy-in was one of the top five ways to respond to the challenges facing the sector, according to the professionals who responded to our survey.

It was suggested that future work could take a more 'campaigning approach', identifying 'key policy shifts' and pushing for those, holding decision-makers to account. Some interview and focus group respondents, as well as vision rehabilitation workers and ECLOs who responded to our survey, highlighted cuts to rehabilitation services as a key issue and suggested that more could have been done to challenge this.

Some interview and focus group respondents expressed disappointment that there had been little visible follow-up to the Public Health Indicator at the level of national government.

It was the view of some that future work has to become embedded in central and devolved government/NHS/local authority strategies, for example through linking into local authority and NHS planning and commissioning processes such as joint strategic needs assessments and health and wellbeing boards:

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"The sight loss sector has to work together more to be a louder voice to government and health service commissioners, it needs to be more pragmatic about the competing priorities that face the health services, and be more impactful about how it articulates the need for and benefits of provision for people with sight loss."

Respond to wider government and health service priorities

There was a general sense that sight loss as a single issue is fairly low on the national agenda, compared with other issues such as dementia or mental health. Some respondents suggested that the most effective way to raise the priority of sight loss on the health agenda would be to link it to other key government priorities including loneliness, mental health and cost saving to the NHS:

"Lack of support at diagnosis can lead to acute depression and taking even more out of the NHS. Need to tap into socio-economic costs. People with sight loss are more likely to fall, break limbs, get depressed - costs that don't impact on life now."

One survey respondent suggested that building a business case would be a helpful starting point:

"Key to achieving the above is the building of the constructive and well-researched case [respondent talked about developing a business case for investing in eye health in a previous response]. This needs to be done with a sense of urgency to an ambitious timetable and to be inclusive of all. This will need significant investment and all parties to understand the value and importance of doing this."

"Once the business case is in place, this can be used to influence politicians and key policy makers within the public sector. Constructive working and speaking with one voice will achieve this - the achievement of the public health indicator for sight loss is proof of this."

Other respondents also suggested that collaborating with other voluntary sector organisations such as Age UK or Diabetes UK might also strengthen the voice to government, particularly in light of the growing numbers of people with multiple conditions and the ageing population.

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Connect with other sector initiatives more effectively

Focus group respondents, particularly from Scotland and Wales, suggested that there was sometimes confusion between the Strategy, their Country Plan and the strategies of the devolved government (See Hear in Scotland and the Eye Care Delivery Plan in Wales). They suggested that professionals tended to refer more often to the government strategies than to the Scottish or Welsh Vision Strategy:

"Other strategies come in – people say that the vision strategy has been superseded by See Hear. Which obviously is a strategy but it's a strategy that's owned by different people for a different purpose. But when there are so many different things around that it's hard to know what's what, which is which and what is the value of this thing that people have been talking about for the last 10 years."

A more devolved approach may be helpful in enabling each country or locality to link in with government, CCG or local authority initiatives.

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4.   Country stories

In this section we consider the Strategy's past work that has taken place in Wales, Scotland, Northern Ireland and England, and discuss potential future work.

This section draws primarily on qualitative data collected at focus groups with each of the country implementation groups and additional one-to-one interviews, as well as survey data from each of the respective countries.

4.1 Wales

Context

The Welsh Vision Strategy states there are 100,000 people living with sight loss in Wales (around 3.2% of the population, 2016) and that this number is expected to double over the next 25 years in line with UK predictions **[33]**.

Eye Care Delivery Plan, Welsh Government

In 2013 the Welsh Government launched the first Eye Care Delivery Plan for Wales. This is a five-year plan that sets out government priorities to improve both eye health and support for those living with sight loss, including both children and adults. Wales Vision Strategy Implementation Group members were involved in influencing the content of the plan and remain involved in its monitoring and in supporting its implementation.

The most recent incarnation of the Welsh Vision Strategy Implementation Plan also references the objectives from the Welsh Government's Eye Health Care Delivery Plan for Wales that relates to the Wales Vision Strategy Implementation Group's aims.

The Welsh Vision Strategy

There has been a Welsh Vision Strategy since 2000 which pre-dates the UK Vision Strategy. From the UK Vision Strategy a cross-sector group was formed to develop and deliver an implementation plan for 2010-14. This was refreshed and launched in 2014 at the Cross Party Vision Group in the National Assembly Government for Wales. The **Wales Vision Strategy Implementation Plan 2014-2018 [34]** is based on the three main outcomes of the UK Vision Strategy and is overseen by the Welsh Vision Strategy Implementation Group. This group is made up of representatives from the statutory, private and voluntary sectors. The plan is available in English and in Welsh.

Looking back: achievements

Collaboration

The strongest sense of achievement was the eye health and sight loss sectors working more closely together. That the sectors were more unified and could present joint responses to consultations was felt to be a significant achievement:

"That is a big success – its biggest success arguably. I think it works well, that it promotes collaboration that we respond to consultation as a Strategy, and that we have representatives. That person x for example will sit on a steering group representing the Strategy… We have a stronger voice in the third sector without a doubt as a result of the Strategy."

The implementation group includes representatives from voluntary, private and public sectors. This has enhanced knowledge of what is going on in the eye health and sight loss sectors, reduced duplication and improved working relationships. It was recognised that there was room for improvement, as explored below but that it was felt to be beneficial for all those who are able to attend the meetings of the Wales Vision Strategy Implementation Group.

Influence on the Welsh Eye Care Delivery Plan

Another major achievement was the influence that the Welsh Vision Strategy had in the set-up of the Welsh government Eye Care Delivery Plan. The members had been consulted and were able to ensure that their objectives were subsumed into the plan. This is acknowledged in the report's introduction. There is some disagreement on how far the Welsh Vision Strategy aligns with the Eye Care Delivery Plan as described below.

Looking back: challenges

Reporting process

For those involved in the implementation group, the reporting in Wales was felt to be a particular challenge. The form was reported to be cumbersome and repetitive. It was also overly long and potentially off-putting for small charities. There was no funding available meaning that all of the stakeholders were doing this voluntarily in addition to busy roles. One of the focus group participants stated:

"We need to step back and consider how to make it as succinct and workable and accessible for everyone."

Complexity and length of the implementation plan

The implementation plan was felt to be needlessly complex. It lists several aims and objectives for each of the outcome areas.

Lack of monitoring and evaluation planning

Similar to findings in other parts of this report, the Welsh participants highlighted that measuring the successes of the Strategy was challenging as evidence gathering had not been set up from the beginning and therefore it was difficult to attribute success.

Attribution issues

There were a number of people involved in the project who questioned whether the advancements in eye health of the last few years would have happened anyway. This is exemplified by the following quote:

"None of the partners in Wales have done work that they wouldn't have done anyway. It wasn't the business [Wales Vision] Strategy that made us do that work."

Small groups and local authorities less engaged

It was felt that there was under-representation from the smaller charities and professionals on the implementation group. This was explained by small groups being under-resourced but also the point above; that reporting was cumbersome and this deterred attendance. It was also felt that more work needed to be done to engage professionals, particularly those from smaller groups and local authorities:

"Professionals are not very engaged - they are not aware of the purpose of the Strategy, outcomes, benefits for them, and what the Strategy can do."

Larger organisations' involvement can be a threat to smaller groups

The need for the larger organisations involved to be careful of not duplicating the work of the smaller collaborators was mentioned as a potentially corrosive area:

"Cross-organisational collaboration is good where it works, but trust is quickly eroded when the big organisations suddenly start doing work that was done by the smaller agencies originally."

Implementation plan not fully embedded in the Eye Care Delivery Plan

In the focus group there was mixed opinion on whether the implementation plan and Eye Care Delivery Plan were aligned. Some felt that they 'do not mirror each other' and others felt that they did but this was not understood or promoted.

However there was representation from the Welsh government on the Welsh Vision Strategy Implementation group and vice versa.

Looking forward

More resources

For those involved in the implementation plan, there was a sense that any future incarnation of the Strategy needed resourcing properly in Wales. In order to be able to raise awareness of the plan and its achievements, to monitor, track and support engagement, both time and funding would be needed.

Improve senior buy-in

There was a sense there needed to be better buy-in from senior staff/leadership in some of the larger charities/organisations. This would have a trickle-down effect and would lead to more commitment from across organisations.

Greater focus on older people

It was also felt that any future plan could better develop support for older people, specifically those returning to dependence on carers or support organisations.

An easier-to-use plan

Any future plan must be streamlined and focused. As one focus group member stated: 'It should be about accessibility and usability.' They felt that the future plan and any reporting requirements should be made easier to use for people with sight loss and available in a variety of formats.

More focus on the built environment

Further research and campaigning on built environment was felt to be a missing area that needed development in Wales.

More focus on improving patient/user experience

Primary care in community settings was discussed as the direction of travel of government policy in Wales and it was hoped that this would be built on solid evidence, meaning that patient care is maximised. Individual care plans need to be cross-cutting ensuring those with multiple conditions are treated in an integrated way rather than in siloes.

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4.2 Scotland

Context

As of 2016, there are an estimated 170,570 people living with sight loss in Scotland, that is, 3.2% of the population). This is expected to rise to 3.4% by 2020 and 4.1% by 2030 **[33]**.

Since the (UK) Strategy was launched in 2008 there have been advances in eye care provision in Scotland. These key changes have included making free eye care examinations available to all and the development of a new system that speeds up the transfer of information between optometrists and ophthalmologists.

There have also been a number of new policies and frameworks that have been introduced by the Scottish government that are of relevance to the Scottish Vision Strategy. Two of these key developments are explored below.

In addition the Scottish Parliament's Cross-Party Group on Visual Impairment brings together a wide range of stakeholders from across the sight loss sector in Scotland, many of whom are also involved with the Scottish Vision Strategy, and seeks to influence policy, legislation and decision makers to better reflect the needs of people with sight loss.

See Hear: A strategic framework for meeting the needs of people with sensory impairment in Scotland

Published in 2014 by the Scottish Government, See Hear provides a framework for meeting the needs of people with sight and/or hearing loss in Scotland.

It sets out a model care pathway and seven recommendations which aim to provide individuals and service providers with a clear understanding of the support that should be provided to people with sensory loss. Through this pathway and its recommendations it aims to provide coordinated and person-centred services and support.

It is delivered by local partnerships, including statutory and third sector partners, who identify local priorities and approaches.

Health and social care integration

The Public Bodies (Joint Working) (Scotland) Act 2014 [35] provided the legislative framework for the integration of health and social care services in Scotland. Integrating these services so as to improve care and support has been one of the Scottish government's top priorities, particularly in the context of an ageing population.

The Act triggered the development of National Health and Wellbeing Outcomes, as well as required NHS boards and local authorities to integrate health and social care budgets. It also strengthened the role of clinicians and care professionals, along with third and independent sectors, in the planning and delivery of services.

To deliver this, many health boards and local authorities have together chosen to create Integration Joint Boards which are delegated responsibility for adult health and social care planning and provision.

The Scottish Vision Strategy

The Scottish Vision Strategy (SVS) was launched in 2008 and was refreshed in 2013. It is led by an advisory group whose members include representatives from the voluntary sector, education, healthcare and statutory services, as well as people with sight loss, referred to as Vision Ambassadors.

The SVS follows the same structure as the UK Vision Strategy with only some small changes made to the priority actions to account for the different Scottish context.

Since 2009 there has been an annual SVS conference bringing together representatives from across the sectors to share progress made and to look ahead to the future.

Looking back: achievements

Engagement with government

In general people felt the SVS had provided a good platform to engage the Scottish government and had helped secure positive engagement with decision-makers:

"Everyone involved with the Strategy has done a great job getting recognition from MSPs [Minister of the Scottish Parliament] and ministers and buy-in. Any conversations that we have about eye care services make a point to link to the Strategy."

Being Scotland-specific helps engagement

The country-based structure was felt to be appropriate because of the Scottish-specific context; it was thought that one UK-wide initiative would be more likely to be ignored in Scotland.

Good progress made by the Scottish Government

Respondents pointed towards the changes made by the Scottish government around free eye tests and the digital link-up between optometrists and

ophthalmologists as being welcome advances, although they did not describe them as being directly the result of the Strategy.

Given a focus for the sector

Some felt the Strategy had been successful in influencing organisations' strategies. Others felt this was difficult to achieve, particularly in the voluntary sector, but that the SVS had been successful in shaping the focus for the sectors:

"Service developments will always be opportunistic – you find a niche and fill it or you find an opportunity for funding and take it. You can't in the voluntary sector say 'we want to do this, this and this' and in five years' time you will have done it, it just doesn't work like that. But what you can do is improve the way that people are knitted in and motivated around the main goals and that can inform what people do."

Brought stakeholders together, particularly at the conference

Overall a key achievement highlighted was the way the SVS has 'got people together and talking'. In particular the Scottish Vision Strategy conference was cited as a valuable addition, bringing people together from across the eye health and sight loss pathway and raising the profile of the SVS. Even if people were not engaged with the Strategy otherwise, they would 'find that date for the conference in their diary'.

Looking back: challenges

Not driven priorities

A disappointment that stakeholders expressed was that the Strategy had not so much driven priorities as just collated work that would have occurred anyway:

"Of course we can review this Strategy every two or three years and ask 'what have we done?' and we can find things that our organisations have done that fit with the Strategy but it hasn't necessarily informed our priorities."

Lack of resource

Some people linked this issue to resources; they felt it was difficult to proactively implement the Strategy when there was a lack of staff time or funding to deliver this. Some thought this lack of resource was the reason why SVS was, as they perceived it, less well known than the UK or **England Vision Strategy [37]**. This lack of resource was seen particularly as a barrier to engaging groups outside the core advisory group/RNIB leads, especially those who were locally-based and frontline:

"If you want to change the folk on the ground there's a big gap […] if you want regionalised stuff there is a cost with that. If we start with a blank sheet of paper

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we could write fabulous stuff about going into the regions, selling it, getting local buy-in but we don't have the resource."

Competing for attention with other strategies

People described the SVS as competing for attention with other strategies or initiatives in this space particularly the See Hear framework. Some people linked this to the age of the SVS describing the first five years as having 'more momentum':

"We've had this iteration of a Strategy for much longer than we would have had a campaign plan – you would normally do that for just two or three years. We have refreshed it but not sure how refreshed it is. People change in the sector and people forget stuff. Other strategies come in – people say that the Vision Strategy has been superseded by See Hear."

See Hear was seen as being more powerful because it came from government whereas the SVS has not had that 'authority' to implement.

Lack of high-level government engagement

More widely people felt that there had not been enough meaningful 'top-level' government engagement with the Strategy:

"We need sustained [top-level government] engagement rather than just 'it looks like a nice Strategy'."

Lack of monitoring and evaluation planning

Challenges were identified around measuring progress on the outcomes. This was described as being partly the product of there being so many outcomes to measure in the SVS' first incarnation and partly again an issue of a lack of resource within organisations. However it was also felt that the evaluation could have been better planned so that outcomes data could be collected in a more 'structured way'.

Competition in the sector

While it was felt that an achievement of the SVS was the collaboration it promoted, it was also speculated by some whether this had been hampered by competition in the sector:

"Some people are competitors so they might have been careful about what they would and wouldn't share, like new ideas or initiatives. Independent leadership could have helped but we also needed internal knowledge."

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Looking forward

More focused priorities

A key comment that people made on the future of the SVS was that its aims and its purpose should be more focused:

"We need to state some of the things we need to change and the end point and to work towards changing those things. At the moment it's quite big and that's why we can fill it with lots of activities."

To achieve this respondents felt there should be some key actions or aims that should be prioritised:

"We need to put in three key priorities which we're absolutely determined to get and start pushing for those."

More action-oriented and dynamic

The key priorities could then include some 'achievable steps', responsibility for which would be assigned to specific stakeholders so it's clear exactly what each are expected to do. In this way it could become a 'change framework'.

As well as making the SVS more actionable, this was seen as also making it more achievable and therefore giving a more compelling message to communicate:

"If we could get something that everyone agreed was absolutely essential and achievable then we would have something that we could communicate more strongly and more positively."

Linked to this there was an idea around making this action plan more 'iterative', with regular monitoring and evaluation of progress. This would help to inform the next iteration of the action plan, making the whole process more reflective and dynamic.

More resource for improved evaluation planning

While this was felt to be beneficial to the achievement of the outcomes, concerns were raised about the need for resource for measurement, and also the difficulty of developing a standard approach across different contexts.

Enable the Strategy to be more embedded in organisations' strategies

More broadly people were keen to see wider engagement with the SVS with organisations taking more 'ownership' of the content and integrating this into their own organisational strategies.

However it was felt that more resource needed to be put towards the SVS if it were to embed further:

"I don't know how you could get the sector to commit to it without some kind of resource or something, people need to see they're getting something out of it […] If there was a dedicated person even part-time then they could really drive it forward, otherwise it's only occasional."

More tailored for and linked into the Scottish context

The context of increasing devolution was seen to be very important and it was felt that a Scottish-specific version of the UK Vision Strategy should continue and perhaps become more tailored to Scotland.

Related to this people wanted the SVS to be more closely linked into other key frameworks and strategies in Scotland to generate greater change:

"It could link into Integration Joint Boards because these are developing agencies that link national and local. They have their own boards and own plans. […] If we could identify the basic standards we expect social care provision to be in different areas of Scotland, that's something that the Strategy could coordinate and try and push policy outcomes that the boards look at and adapt the minimum and optimum standards."

Although See Hear was discussed as being more 'authoritative', as described above, people still felt there was a need for the SVS as well because they were for different groups and had different emphases:

"I personally think there's a need for both. […] I think certain clinical services find the SVS better, See Hear focuses on social care more. So there are pros and cons. The SVS needs to sit alongside and link into See Hear as much as possible."

Linking in with national initiatives was seen by some as being the most effective way to influence practice across the country rather than also trying to operate directly on the local level:

"The biggest impact might be trying to do something nationally. Below that there's all the work on the ground. Local people are very good at that. Maybe it is two-tier rather than accepting it as one. You can't do everything."

Lobbying government on key policy issues

As part of this some respondents suggested that the SVS should identify 'a few key policy shifts' to push for. This was felt to be a 'more realistic outcome' for the SVS rather than trying to measure everything that is happening 'on the ground':

"There's some things which the government aren't as forward-thinking on which the Strategy should pick up as main action points and keep pushing the government on them."

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4.3 Northern Ireland

Context

There are currently an estimated 51,410 people living with sight loss in Northern Ireland **[33]**. This equates to 2.8% of the population, although this is expected to rise to 3.1% in 2020 and 3.8% in 2030.

The Northern Ireland Executive, through its Department of Health, funds the delivery of health and social care services in Northern Ireland. Health and Social Care in Northern Ireland (HSC) is the body that delivers these joint services. Services are commissioned by the Health and Social Care Board which is accountable to the Health Minister.

In 2011 the Transforming Your Care review recommended a wide range of changes to health and social care in Northern Ireland in order to ensure that services could meet present and future demand. These included prioritising prevention and early intervention as well as delivering more care in the community. These changes are now being implemented, led by the Health and Social Care Board.

The Northern Ireland Vision Strategy Implementation Plan

The **Northern Ireland Vision Strategy Implementation Plan [38]** was first established in 2008 with its current version running from 2014-16. It is led by the Northern Ireland Vision Strategy Implementation Group, which is made up of a wide range of statutory and voluntary organisations and professional bodies, and chaired by RNIB Northern Ireland. This includes a close partnership with seven government departments.

Looking back: achievements

Support from government

Many people were pleased that the Northern Ireland Executive has been broadly supportive of the Northern Ireland Implementation Plan (NIIP). For example, in the past the Northern Ireland Implementation Group (NI Implementation Group) had written to ministers and they had responded by nominating someone from their department to join. As a result there is very good representation on the NI Implementation Group from a wide range of government departments.

Cross-sector collaboration

It was felt that this collaboration has helped to develop positive relationships between government and non-government stakeholders working on sight loss issues, particularly in the voluntary sector:

"We felt it had created a focus for sight loss issues - a positive and constructive opportunity for the voluntary sector to engage with government, which might have been lacking in the past where the voluntary sector might have been a bit of an annoyance to government. But I think it's changed that engagement."

These cross-sector relationships were described as very healthy, albeit occurring more on an operational rather than a strategic level, and that the NIIP gave them a 'shared vision and direction'.

People felt the NIIP provided a unique forum for the sharing of information and activities around sight loss. The NI Implementation Group was seen as a helpful structure to support this communication:

"We thought it had also proved to be a valuable way of sharing information of sight loss issues and the activities of different departments and different organisations around the table."

Improved cross-departmental working within government

Within the government the Strategy was seen as having improved communication and collaboration across departments as well. This was around working together to encourage people to consider sight loss issues more, both up and down the structures of government:

"It's created a vehicle for government departments to engage with their arm's length bodies. So they've got agencies and other bodies delivering services to the public and it's created a purpose in engaging them with sight loss issues, to say look you've got to be aware of this, conscious of this."

"We feel on a departmental level it has improved our cross-departmental working and not to silo and also in terms of sector organisations and then communication between that level and up to government."

All of this was felt to mean that the NIIP may have brought new awareness of eye health and sight loss to the development of government strategies although this was only described tentatively as a potential 'indirect' result.

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Unified voice for the voluntary sector

Within the voluntary sector there were comments that the NIIP has 'unified its voice' and that there was good buy-in from community organisations.

Well known among sight loss specialists

The NIIP was described as being well known among sight loss specialists although 'not much wider than that'.

Implementation plan allows tailoring for the Northern Irish context

The structure of having the Northern Ireland-specific implementation plan was thought to be very helpful as this meant it could bring out Northern Irish 'nuances and priorities' and that they could 'work it out at a regional level'.

Audiovisual bus announcements in Belfast

Finally, in terms of tangible changes to services, several respondents talked about the introduction of audiovisual bus announcements in the Belfast area. While this was welcomed it was also highlighted by some that this should now be rolled out more widely across Northern Ireland.

Looking back: challenges

Not driven new action

Considering what has been challenging or disappointing around the implementation in Northern Ireland, some people felt the NIIP had only influenced the government where it fitted with their existing plans, rather than the needs of people with sight loss, as presented in the Strategy, truly shaping government programmes.

Some people expressed the opinion that the 'achievements' of the NIIP would have happened anyway and that the NIIP has not 'thrown down challenges to do something new'.

Not fully embedded into the programme for government

Related to this some people were disappointed that the NIIP was not more embedded into the programme of the Northern Ireland Executive and this made it vulnerable to 'losing out to other priorities':

"So when the chips are down and our colleagues are told to deliver x, y and z, the [NIIP] will not appear on that list because it's not something the Executive is actually committed to."

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Difficult to keep a wide range of government stakeholders engaged

Another challenge that had been faced in engaging with government was the need to engage a wide range of departments and individuals:

"The fact that we don't have a minister [for disabilities] means that there isn't really a focus on some of these things. Or a single point of contact for disability issues and it becomes quite disparate then. We're trying to engage with each department and make sure everyone's aware of what we're asking for and build those relationships across the board."

Action has been piecemeal and not 'joined up'

There was also a challenge around how to join up the work of different stakeholders, particularly different government departments and that the work around the NIIP was sometimes too 'piecemeal':

"We say our own piece and go again – don't know who's joining the dots."

Unsure to what extent NIIP represents the voice of people with sight loss

Some people questioned to what extent people with sight loss felt the NIIP represents their 'voice':

"How well do they feel that this represents what they need and want?"

Lack of resource

There was a challenge around resources: a lack of time and money for both government and voluntary organisations, which was felt by some to have been a barrier to realising some of the actions.

Outcome 3 is too broad

Considering the Strategy's outcomes, several people felt that too much had been 'shoehorned' under Outcome 3 leading to them not getting the attention they need:

"So we had employment, education, skills development, travel and transport and a whole host of little things under participating in society, including digital inclusion and healthy lifestyles and public appointments processes, so we've had a whole load of stuff shoved in there."

Children and young people's needs are overlooked

Some people felt this was partly why the needs of visually impaired children had been 'overlooked'; because outcomes or actions specifically for children were not stated, some people felt their specific needs got 'lost' in the breadth of Outcome 3:

"A lot of the things that people need get squashed into the last priority and what happens in that case is a lot of adult issues get maximised and the children's issues – if you find them on page 32 you're doing well."

This was seen to be exacerbated by the fact that children's sensory services were already perceived as neglected in Northern Ireland:

"That is reflective of Northern Ireland, where children, certainly in terms of health, very much the Cinderella services of adult services, and sensory disability is very much the Cinderella of disability services. So you have a way of undermining your plan before you've started if you continue with what you have."

Looking forward

Closer collaboration

Thinking ahead to future work many people said they felt there were opportunities for closer working particularly between government, voluntary sector and healthcare. It was felt that through greater collaboration more could be achieved:

"I think that's what we found whilst developing the new accessible transport Strategy - to deal with issues not separately, but together […] It's all the same, one battle. There's opportunities there to work more closely together."

The recent government restructure that took effect in May 2016 was highlighted as an opportunity in this context because of the way it brought together issues relating to people with sight loss under fewer departments, particularly the Department for Communities.

Building working relationships

To achieve this some people felt it was about building relationships between key individuals to gain genuine working relationships:

"It's great having the various groups, the VSSG [Vision Strategy Steering Group – the Northern Ireland Vision Strategy implementation group], the All Party [The All Party Group on Visual Impairment] but beyond those meetings it's good then, on an operational level, to make sure we are aware of the key contacts to really see implementation moving forward."

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Identify champions in government

There was an idea to identify someone from each department as a 'vision champion' who could advocate for the needs of people with, and at risk of, sight loss and also could help facilitate consultation with them.

Tie into the priorities and approach of government

Linked to this, people were keen to see greater integration of the NIIP with the structures, priorities and approach of government. It was felt that this would mean the Strategy was likely to make more progress on its outcomes if it were more embedded into the programme for government:

"We talked about trying to mirror or get our points from our Strategy across and look at the other departments' strategies – to see where we're both pushing the same direction. Because if we can identify those areas then I think we have more of a chance of getting the departments to move on it. Because it also impacts positively on their Strategy as well."

It was specifically noted that there was a need to tie the NIIP into the Northern Ireland Executive's outcomes approach and also some Northern Ireland-specific legislation, for example, the Special Education Needs and Disability Act and the Cooperation Bill, highlighting the continuing need for a Northern Ireland-specific implementation plan.

Influence government policy

There was a suggestion that the Strategy could influence departments' work through getting a 'high-level indicator' into, for example, annual commissioning plans. There was also an idea around pushing for a new piece of legislation that would enshrine the rights of people with sight loss, in the same way that there had been a law created to protect autistic children, that would 'fundamentally change the relationship with people with sight loss' and their 'position in society'.

Influence senior or elected government stakeholders

More broadly some people felt there was a need for the Strategy to 'shout louder' to government, and to influence more senior and elected positions in particular: 'lobbying MLAs (Members of the Legislative Assembly) and people who sit on steering groups'. It was felt this would create a greater profile for the NIIP and hold departments to account more effectively:

"I can say MLAs have asked this question, and it gets my attention – it's a challenge for the future. It raises the profile and gives the opportunity to ask for more resource."

More freedom to tailor action for the Northern Irish context

Reflecting on the need for a Northern Ireland-specific approach, some people questioned to what extent the approach and outcomes of the UK Vision Strategy were necessarily the most relevant for Northern Ireland and suggesting that a unique Northern Ireland Strategy could be more relevant.

Some more resource, but also more focus

Considering the question of resources some people felt that more time and money was needed in order to drive forward actions and to pilot new initiatives. However others felt it was more about bringing more focus and awareness rather than necessarily about having more resource:

"It's about getting people together to recognise and realise that maybe things aren't being done right or aren't being done enough. And then getting the focus back to the people that are delivering on the ground. […] Yes sometimes there's initial outlay but that shouldn't always be the key focus, especially when you're trying to look at it in a way to do it better but not necessarily with the cost, because we don't have money."

More focus on prevention, early intervention and continued support

In terms of what future work should focus on, prevention and early intervention was a key theme, for example, raising the profile of regular eye tests. This was felt to be an effective way of reducing healthcare costs in the future and people were keen to learn from other countries who have taken a preventative approach:

"[Outcome 1] is a very very generic, broad statement and we felt that we wanted the word prevention or preventative approach in there somewhere, to make people realise that prevention is better than the cure. If we can stop 100,000 people getting severe eye conditions as a country we're quids in further down the road."

However this call for more focus on preventative work was also followed by reminders of the need to 'balance' this with support for people who already have sight loss:

"So how do we have balance for people who are already there? And that probably links into everything being thrown into the inclusion side of things for the people who are going to be visually impaired for life or a significant proportion of it anyway."

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More focus on sharing and replicating good practice

Considering Outcome 2 some people felt that it was also too broad and that it should focus more specifically on sharing and adopting good practice as part of 'streamlined' services:

"We need to look at what [departments] are all doing then pick out the good things they are doing and get everyone to try … So we very much feel that we should be streamlining the services to allow for the early intervention and support."

Link more to the equality agenda and international frameworks on this

It was felt using the word 'equality' in Outcome 3 would make it more powerful, tying it into one of the priorities of the Northern Ireland Executive but also providing an opportunity to link into European legislation and the relevant United Nations conventions, such as the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention of the Rights of Persons with Disabilities (UNCRDP):

"Look at the European legislation, it has very specific requirements for how governments do provide services for people and again if we map across for what we are asking for … to say that we're not thinking this up on the back of a fag packet here, but this is actually enshrined in European law and we should be doing this."

"We need to look at some of the legislation specific to Northern Ireland … but equally that needs to be underpinned by the UNCRDP and UNCRC in terms of the higher order things that government is asked about as well."

Children's needs should be specifically addressed

Some people felt that within future work the needs of children should be specifically addressed. This was partly because it was felt to be the right thing to do in terms of considering the long term view, because children and young people are 'very important for the future of the planet'. But also because it was felt that if children were not identified as having specific needs they would be overlooked:

"We had a distinction between… inclusion for children, inclusion for adults – obviously it's all these things but I was making the distinction that if you just put the children into the inclusion one again [the current Outcome 3], you will get [children's needs] downgraded again and again."

Consider inclusion in all aspects of life

Alongside this there were calls to think about the concept of 'inclusion' in a broader, holistic sense so that people have the opportunity to be independent and fully involved in all aspects of life specific to the 'age and stage of life they're in':

"So if we put AV on all the buses, that's not inclusion sorted, that's one element of it sorted. Are these children trained, do they know how to use public transport safely? So it's really inclusion from the much much broader perspective."

4.4 England

Context

In England, as a significantly larger country than the other three UK nations, the estimate for those living with sight loss stands at 1.7 million **[33]** which is 3.2% of the total population. As described in the background section 2 above, the infrastructure of publicly-funded eye health and sight loss services through NHS England and CCGs is distinct from the other countries.

Since the UKVS team and Vision Strategy Leadership Group are primarily based in England it was sometimes difficult to identify whether changes described by respondents in England were a result of the Strategy or the England Vision Strategy (EVS) or EVS' predecessor: the England Implementation Group. For completeness we have included in this section the responses of all those with an England-specific remit but there will be inevitable overlap with the UK-wide findings described in Section 3.

The England Vision Strategy

The England Vision Strategy Implementation Group was formed in 2008 and was composed of a large number of representatives from across the eye health and sight loss sectors. This group published the England Implementation Plan 2009 – 2014 and also created a work plan for organisations to take responsibility for each priority action.

The EVS was created out of the England Vision Strategy Implementation Group in 2014.

Since 2008, working with the UKVS team, over fifty local Vision Strategy groups have been established throughout England to deliver change at a local level with their work expected to be incorporated into the EVS over time.

The EVS is now supported by a dedicated staff team funded by the Thomas Pocklington Trust (TPT).

The current **England Vision Strategy [37]** was launched in 2015 and is due to run until 2018. It lists six priority areas separate from the UK Vision Strategy's three overarching outcomes. These are:

1. Detecting eye conditions early, especially in seldom heard groups.

2. Promoting a consistent strategy for eye care commissioning.

3. Improving the certification process – making sure people who are eligible

actually get certified and registered and that relevant data flows through the whole eye health and sight loss pathway.

4. Early intervention to ensure practical and emotional support post diagnosis (for example, an ECLO available in every eye department).

5. Habilitation and rehabilitation available on a free and timely basis for as long as needed to learn or relearn key life skills including mobility.

6. Development of peer support and self-help groups in every community for adults, children and families to provide voluntary sector support for independent living and to lobby for inclusive local public services

The EVS has both an executive and a consultative group. The executive group comprises cross-sector representation from leading organisations in England working on eye health and sight loss. The consultative group includes a range of stakeholders from across the country and meets twice yearly.

The executive is supported by excellence groups. There are five sub-sector groups representing:

- children and young people
- ophthalmic public health
- optometry and ophthalmology
- post diagnosis support, rehabilitation, and low vision
- voluntary sector good practice.

The EVS is delivered across twelve geographical areas ensuring local authority areas and CCGs are subsumed under one of the geographical areas.

Looking back: achievements

Carefully selected priorities

The England Vision Strategy (EVS) focus group was particularly candid that the EVS priorities (listed above) were partly opportunistic and explicitly built on what some organisations were already doing.

Informed local organisations' practices

There were a number of examples where the EVS had informed local organisations' practices and noted as beneficial:

"The six priorities have changed what we as a local organisation do. Really good to align having this with what local people do, and also good to have

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the regional one. I talk about it when I go to other organisations. We've moved on a long way in a short time."

Regional structure

Another achievement was that the EVS had brought key stakeholders together in a meaningful way:

"One of the reasons why things are improving is that we have developed a regional structure – can bring people together in the same room in areas that make sense to them, rather than trying to do it nationwide."

Groups

The regular group meetings were felt to be beneficial to bringing the strategy alive:

"One of the strengths of the EVS consultative group is that it's not just a piece of paper you stumble across – you can get together in the sector and do it. Anything that can help it not feel like just a piece of paper would be helpful."

A platform for all

Another strength was that the EVS was accessible and uncontroversial:

"One of the most important things about the Strategy [EVS] is that it's fairly easy reading – no one could be entirely against it – and it's created a platform on which different policies can be based."

It was felt that the EVS covered the whole pathway of eye health to sight loss and that this was useful to understand where people are:

"It has set out the entire pathway – from early detection right through to living with sight loss – its success is that it enables people to see their place in the pathway and how they relate to people on either side."

Improved inter-organisational relationships

Some respondents from England described how working relationships between different eye health and sight loss organisations and services had improved with organisations who previously 'wouldn't sit down in the same room' as one another now working together:

"There are lots of organisations that are now part of the same family."

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Looking back: challenges

There were several challenges raised throughout the evaluation regarding the Strategy. Many of these contradict the points above, demonstrating that people are divided on the overall success of the Strategy.

Competition limiting collaboration

Respondents felt that funding had limited what the Strategy could achieve. The example given was that scarce resources had hindered collaboration:

"In an age of austerity, cross-organisational collaboration hasn't been the best, everyone seems afraid to share practice because of fear of losing funding or services."

Demotivation in the sector due to a lack of investment

Funding was an issue that affected the whole sector. One respondent noted that many years of waning funding had resulted in people giving up:

"Most professionals are disheartened by chronic lack of investment in services and after trying for years, even decades in some cases to improve services and receiving no support, they have mostly given up."

Plans not sufficiently actionable

There was a sense that the Strategy had not gone far enough with one respondent stating '(The) current plan [EVS] needs more teeth to be effective'.

Resources too concentrated in the south

It was felt that the north of England had been overlooked. The respondent felt that some progress had been made but generally it was felt that more representation was needed:

"New setup with joint heads seemed very London centric – it took forever to get off the ground. Now that [TPT] has an office in Birmingham that helps but the North is a desert – people knew about the UKVS and ending avoidable sight loss by 2020 but people didn't really know what it was. If I talk to people in voluntary organisations in the Midlands they know what it is but it's not high on the priority list. It's patchy – pockets of wonderful stuff and then nothing."

Need for clarity on what the Strategy is trying to achieve

Some felt the Strategy had been confusing at first and that they were not confident in saying what it was trying to do:

"New to role at charity – would concur that it's confusing. Aims of strategy are a little diffuse – not sure I could clearly say what it's trying to achieve."

Lack of infrastructure to engage eye health networks and CCGs

It was felt there had been missed engagement opportunities and this had only really been focused on in the last two years:

"We've missed many opportunities to really engage with the eye health networks or CCGs because we had to cover them one to one. Great if you know of us. We realised relatively late that there was no infrastructure to engage with those people, we've only started doing that over the last two years. The strategy is a great thing, but it's a policy document, not an implementable policy document."

Larger and more complex decision-making structures in England

Some of the respondents felt that the Strategy had been more successful in the other small nations where decision-making was not as complex as England:

"It has been more successful in Scotland, Wales and NI. That's inevitable as those countries are more cohesive and smaller. The decision making is simpler – in England you have to convince CCGs again."

Looking forward

More focus on eye care from public health

Respondents felt that more work needs to be carried out in England to inform the public of 'how sight loss fits into the wider public health context' in order to raise understanding of how important eye care is for individuals.

Another person noted that England could follow Scotland by ensuring that all over 60 year olds should have their eyes dilated routinely for every sight test.

At one of the VSLG meetings a member commented that if sight loss was redefined as 'a chronic condition' it might get more attention and funding.

More focus on prevention

It was felt that future work needed to focus on both sight loss and prevention as these were the points in the pathway where most of the problems lay:

"All the conversation around the table has been about living with sight loss and less about prevention. The Strategy needs to recognise that much more and focus on it because that's where the difficulties and problems lie."

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Increase funding for service provision

Funding came up on many occasions for future-focused work including funding for more ECLOs, rehabilitation workers, sensory impairment support and eye clinics.

More resource to raise the profile of the Strategy and secure buy-in

It was felt that in order to secure more funding for eye health, the CCGs would need to be brought on board.

"Still need to get the CCGs on board and unless there's extra funding nothing will progress."

Some people noted that resource was needed more generally to implement the Strategy and raise its profile:

"But the problem is the resource available. We have put in a lot of resource over last couple of years – RNIB as well and others – it's needed that to help things to happen. Having the Strategy on its own doesn't help."

More specific responsibilities for organisations

Respondents felt that more work on improving collaboration across the sectors is needed and specifically, organisations should be encouraged to sign up to actions:

"Cross-organisational collaboration exists but as each organisation is not bound by any of these 'strategies' and has their own goals and priorities - collaboration is producing limited results. Perhaps pledges, with specific targets, for each organisation to sign up to would add value."

Increase awareness of sight loss issues

Some felt the next incarnation of the Strategy should involve significant work on changing the public perception of sight loss in a way that makes it compelling:

"The reality of life is that the public perception … the focus of life now is Alzheimer's, breast cancer and all of those things with resonance. The perception of anything to do with eye health has gone down the scale and doesn't resonate… A lot of this is inward looking."

Connected to this some people felt that medical professionals, specifically doctors and nurses, should have better and more training around eye health and sight loss issues.

More rehabilitation support

Rehabilitation support was mentioned on a number of occasions. This support was felt to be fundamental in building confidence and preventing isolation:

"Support to get out and about independently, support to use assistive technology and support to re-learn day to day tasks. The more empowered a person is, the more confident they become. They are also much more likely to create connections in their local community and become at less risk of becoming isolated and likely to reach a crisis situation."

Link to political agendas to increase buy-in

In any future incarnation of the EVS political buy-in was felt to be a must. It was felt this could be achieved by highlighting links to areas of political interest such as concern over growing numbers of people with dementia and efforts to decrease pressure on hospitals:

"Get political buy-in to the agenda. Link to things that they are already interested in e.g. dementia, keeping people out of hospital. Use their language, adapt it and send it back to them."

Clearer pathways

Some of the respondents stated that they felt confused by eye health services and hoped for a 'clearer structure for eye health services so that it is more efficient and more patient friendly/accessible'.

Having clear pathways supported by NHS England was seen as important:

"Need standardised community care pathways and need NHS England to endorse them."

Transferring more care to community settings

One of the respondents had some specific ideas about eye professionals and delivering more care in the community. They felt optometrists needed to be less isolated and that care could be more effectively delivered if optometrists were upskilled to deliver more eye services in community settings.

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5.   Conclusion

In this section we provide our conclusions based on the data we have collected and the background research we have done. There are two sub-sections: first, the achievements of the Strategy and second, the learning for the future shape of work in eye health and sight loss.

5.1 Progress towards the Strategy's three outcomes

Overall our data shows there has been some progress towards each of the three outcomes in the Strategy. However in all three cases there were strong calls for more to be done.

We are not able to attribute any direct achievements to the Strategy due to the broad nature of the stated outcomes, the lack of a theory of change or statements/ targets of success, and the lack of systematic monitoring and evaluation. Also the Strategy is not well known by people with sight loss so even if changes have occurred that relate to the Strategy the connection may not have been made by our research participants.

In light of this we have only been able to review the data to see what progress has been made towards the outcomes listed in the Strategy and to share people's perceptions of whether or not the Strategy has contributed to this progress.

Our conclusions are as follows:

The perception is that there has been some progress towards **Outcome 1 (everyone looks after their sight and eye health)** because there has been an increase in public messaging on this subject. However more needs to be done to raise awareness through more public education and better support.

There has been some progress towards **Outcome 2 (timely treatment and appropriate support)** in so far as some reported a more seamless pathway and improved services, particularly more ECLOs. However there was a strong feeling that more needs to be done on Outcome 2 to:

- improve availability and accessibility of support
- focus on preventing avoidable (and currently unavoidable) sight loss, for example through early detection and further research on treatments and cures
- continue working towards a more seamless eye health and sight loss pathway.

Some progress has been made towards **Outcome 3 (full participation in society)** as transport, technology and information are becoming more accessible. However there was a strong call for more to be done to increase public understanding of the realities of living with sight loss and for taking an asset-based (rather than a deficit-based) view of people with sight loss, focusing on what they can do rather than on what they cannot do.

The background factors of declining funding, an ageing population and demand for services being greater than supply are going to make future progress challenging. However it is worth celebrating progress to date.

5.2 Learning for the future

Our analysis of the data brings out some key themes that represent other achievements of the Strategy as well as lessons that have been learnt during 2013-16. Many of these issues are considerations for both the remaining life of the Strategy and for shaping the future. They will help both with deciding **what** the focus should be and **how** the work should be organised and implemented.

Fragmentation

People have been brought together from across the eye health and sight loss sectors. This was seen as an achievement of the Strategy. However more needs to be done to reduce fragmentation and increase collaboration locally and nationally, and across the voluntary, public and private sectors. There is a call for thinking about where joint working can really add value and achieve synergy to have an effect that is greater than the sum of the parts.

Involving people with sight loss

Some people with sight loss have been involved with the current Strategy and ought to be involved in any future shape. However, awareness of the Strategy among people with sight loss has been low and so better communication needs to be in place for the future. People with sight loss also need to be more directly involved in the implementation and governance of this work.

The role and nature of the Strategy

The Strategy was seen as being a single, unified voice for the eye health and sight loss sectors with relevant outcomes which has catalysed the formation of local groups. However there is confusion and mixed feelings about various aspects of the Strategy including its status, role, reach, leadership, governance and implementation.

These aspects need to be thought through and addressed. In addition, the question of having a Strategy at all is worth asking and, if so, whether to continue to pursue broad outcomes and/or to have more detailed outcomes, and whether a monitoring and evaluation framework and sharing of learning would also be useful.

UK-wide remit

Devolution has had a positive effect in Wales, Northern Ireland and Scotland in that governments in the devolved nations have been more willing to engage in the Strategy than in England and the influence on these governments has been greater. However there is a lack of resources in these nations which has affected the rate of progress. There is a question about whether a UK-wide Strategy is still required.

Connection with governments

High-level buy-in has been good among some governments especially in the devolved nations. The Public Health Indicator is perceived to be the Strategy's greatest achievement. However more needs to be done to link the Strategy (if it continues) to (a) all governments' health and social care priorities and (b) other relevant sector initiatives.

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6. Recommendations

The NCVO CES and UKVS teams facilitated a half day workshop with a variety of stakeholders to draw out recommendations from the validated findings of the review and consultation project **[39]**. The NCVO CES team took the notes from this workshop and reviewed them in light of the data collected and conclusions arrived at before including them in this report. In making these recommendations we have considered:

- learning that has emerged from the data collected through the 'looking back' review of the Strategy so far

- emerging issues that are currently at play and likely to form the backdrop for future work in eye health and sight loss beyond 2018, which was gleaned from the consultation data that invited people to 'look forward' and give their views.

The recommendations below fall into two categories: **what** could future work focus on and **how** could future work be organised. We give our recommendations as options for consideration rather than firm prescriptions. This reflects the mixed findings from our data.

6.1 What could future work focus on?

The outcomes of the current Strategy are still relevant as a focus for future work so they should continue to be the focus for future work. In addition we recommend that the following are considered:

- The key messages and best ways to increase public awareness of eye health and looking after sight.

- Getting more research for treatment and cures underway, for example, asserting direct pressure on national government or other funders, working with or supporting others who may be asserting this pressure.

- Further work to understand what barriers exist for people who are not accessing current support and how best to tackle this.

- Reviewing the Adult UK eye health and sight loss pathway, the Seeing it my way outcomes and the commitment to a person-centred approach with relevant stakeholders to better understand what has and has not worked to make the pathway seamless. For example, consider co-creating a theory of change that all relevant stakeholders are bought into and which

prioritises outcomes for people with sight loss. Take inspiration from other sectors that have achieved high quality, integrated services.

- Taking an asset-based approach rather than a deficit approach to change the narrative about people with sight loss to be about what they can do (rather than what they cannot).

6.2 How should future work be organised?

We suggest a number of practical considerations with regard to how best to organise future work:

Decide whether the Strategy is a coordinating body or a direct actor

Consider whether the Strategy outcomes should be a direct actor with clear goals or a coordinating body to which various stakeholders report their achievements.

Direct actor

If the Strategy outcomes are goals, then the Strategy becomes a 'doing document' and further clarity needs to be added. For example:

- each outcome could be further detailed into intermediate outcomes

- prioritisation of outcomes per nation (for example) could be carried out

- clear measures of success/indicators should be defined and regularly monitored, recorded and shared as evidence to demonstrate achievements as well as to learn and improve

- task and finish groups could be set up for specific projects.

Coordinating body

If the Strategy is to be a coordinating body, then it would be worth considering:

- reviewing the 'value add' of having a Strategy: does it enable organisations to achieve together what they cannot on their own? In addition, creating a think piece or charter to which various stakeholders subscribe

- whether there should a UK-wide body or per nation bodies or both

- collaborating to create a 'theory of change' into which all relevant stakeholders are bought into.

Coordinate and communicate work more effectively

If a UK-wide Strategy is deemed important post-2018 then consider:

- rationalising the superstructure
- firming up national/local/sub-regional infrastructure
- being clear about the country specific remit and reach
- how best to communicate the purpose of the Strategy and show how it relates to work happening in existing organisations
- revisiting terminology. For example,
  - consider replacing 'Strategy' for something more current and accessible
  - consider if the term 'pathway' is accurate and appropriate.

Involve people with sight loss more

Involve people with sight loss in:

- decision making, defining and leading the way forward
- co-creating and communicating key messages.

Tell stories

Tell people's stories of the realities of living with sight loss. Factors to consider include:

- linking sight loss stories into disability awareness more generally
- going into schools, workplaces and places of leisure to reach more people.

Run campaigns

Run simple, public-facing campaigns to raise awareness of the importance of, and improve positive action on, eye health. Factors to bear in mind include:

- taking a segmented approach rather than a mass public campaign may work better
- how well people are responding to campaigns that are already running, (for example Specsavers) as there is a perception that existing campaigns are not having a big effect. It would be worthwhile to find out why and what can be done better/differently to increase response.
- have a clear call to action as part of the campaign.

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Continue influencing

Continue working to influence local and national government and related organisations to secure buy-in and pay more attention to sight loss and eye health.

Also consider influencing leadership especially with a view to supporting charismatic/disruptive leadership to challenge authorities, change culture and speak with a clear voice on the issues of eye health and sight loss.

Encourage collaboration

Encourage collaboration with other organisations/coalitions within the sight loss and eye health sectors and work towards encouraging a cultural change so that organisations:

- find ways to pool resources and local knowledge

- avoid duplication

- work collaboratively

- increase the amount and quality of support for people with, at risk of, or affected by sight loss

- collectively and consistently message the public on important matters.

Consider the implications for devolution

In the event that no further funding is forthcoming, consider how best to allocate finite resources towards achieving priority goals and to perhaps find creative ways to attract other resources such as volunteer time and pro bono offers.

Develop quality and self-assessment

Quality standards and self-assessment might be useful for the eye health and sight loss sectors. For example, the following might be considered:

- Developing a national standard/s to which all those working in the eye health and sight loss sector can aspire to and work towards.

- Designing a 'template of good practice' against which organisations can self-assess.

- A catalogue of examples of good practice, such as one stop shops where people receive information in one place about all areas of support, people's stories of good quality service and/or joined up support.

- Find mechanisms by which to share learning and develop services further.

- Create a simple, effective dashboard of indicators for all to access and feed into.

7. Appendices

There are five appendices in this section:

1. Links to the two surveys and the toolkit used for the collection of data.
2. Additional data from (a) professionals' survey and (b) people's survey.
3. Lists of member organisations on the (a) Vision Strategy Leadership Group and (b) Country Vision Strategy Implementation Groups.
4. Glossary and definitions.
5. List of references.

7.1 Links to surveys and toolkit

An MS Word version of the Professionals' survey can be found at
http://bit.ly/2hsBKnx

An MS Word version of the survey for people with sight loss can be found at the following web address: http://bit.ly/2giy8Dk

An MS Word version of the toolkit for organisations that enabled them to run their own consultation events can be found at the following web address: http://bit.ly/2hRQYCr

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7.2 Survey data

Professionals' survey Demographic information

209 respondents completed the professionals' survey. Of these, 165 told us which country of the UK they work in, and this is summarised in the following table:

Which nation of the UK do you work in?		
Answer Options	Response Percent	Response Count
England	73.9%	122
Across the UK	9.7%	16
Scotland	6.7%	11
Wales	6.1%	10
Northern Ireland	3.6%	6
answered question		165
skipped question		44

17% (27) of professionals in the survey had sight loss. This is too small a number from which to draw any firm conclusions. Of these, 11 work for a sight loss charity, 4 as ECLOs, 2 as optometrists and 7 in other professions including QTVIs.

Of 210 respondents, 158 specified their professional role. The spread of occupations is shown in the following table:

What is your professional role?		
Answer Options	Response Percent	Response Count
Work for a sight loss charity (please specify)	29.1%	46
Eye care liaison officer	15.8%	25
Optometrist	9.5%	15
Orthoptist	8.2%	13
Vision rehabilitation worker	8.2%	13
Ophthalmic nurse	3.2%	5
Ophthalmologist	2.5%	4
Education professional, eg, QTVI (please specify)	2.5%	4
GP	1.9%	3
Occupational therapist	0.6%	1
Nurse practitioner	0.0%	0
Specialist nurse	0.0%	0
Habilitation officer	0.0%	0
Other (please specify)	18.4%	29
If you have been asked to specify your answer, please do so here:		64

Of those who selected 'other', 25 specified their roles and there was an extremely varied range of roles that do not lend themselves to easy classification. The roles included QTVIs and other teachers, dispensing opticians, civil servants and a manufacturer of instruments for screening.

Of those who work for sight loss charities, 33 gave further information. 13 work for RNIB, 2 for TPT, 2 for VISION 2020 UK, 1 for Guide Dogs, 2 for Action for Blind People, 1 for Macular Society, 1 for Deafblind UK, 5 for local charities. Others gave information about their role rather than the organisation they worked for.

Including orthoptists, 40 respondents (25%) represented the eye health part of the pathway and the others represented the sight loss part of the pathway.

Just under half of all respondents had worked in the sight loss sector for more than ten years. The following table provides more detail:

For how long have you worked in the eye health and/or sight loss sectors?		
Answer Options	Response Percent	Response Count
Less than 1 year	5.3%	8
1-2 years	10.5%	16
3-5 years	15.8%	24
6-10 years	20.4%	31
More than 10 years	48.0%	73
answered question		152
skipped question		57

Key statistics

Just over 90% of the professionals who completed the survey had heard of the UK Vision Strategy.

156 professionals answered the question about how far the UK Vision Strategy had contributed to achieving its outcomes. Their responses are summarised in the following table:

How much do you think the UK Vision Strategy has contributed to achieving these outcomes?		
Answer Options	Response Percent	Response Count
Don't know	42.3%	66
Minor contribution	29.5%	46
Major contribution	24.4%	38
Not at all	3.8%	6
Please comment on your answer here:		80
answered question		156
skipped question		53

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Survey for people with sight loss

An MS Word version of the survey for people with sight loss can be found at the following web address: http://bit.ly/2giy8Dk

Demographic information

Geographical distribution

315 people in total responded to our people's survey. Of these, 78% live in England, which is broadly representative of the distribution of the population registered blind or partially sighted.

According to the RNIB's **Living with sight loss report** the national distribution of the registered population is as follows:

Registration by country:

- 299,000 in England (83.5%)
- 34,500 in Scotland (9.6%)
- 16,500 in Wales (4.6%)
- 8,200 in Northern Ireland (2.3%)

Our survey results are as follows:

- 244 in England (77.5%)
- 31 in Scotland (9.8%)
- 17 in Wales (5.4%)
- 23 in Northern Ireland (7.3%).

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Age

Over 75% of the registered blind or partially sighted population in the UK is aged over 65. Our survey therefore does not reflect the age distribution of the UK registered population. Our survey results are in the following table:

What is your age?	
Answer Options	Response Percent
16 - 24	8.3%
25 - 34	10.8%
35 - 44	11.4%
45 - 54	23.2%
55 - 64	26.7%
65 - 74	12.4%
75+	5.1%
Prefer not to say	2.2%

44% of our survey respondents were aged over 55 and 17% aged over 65.

The registered population has the following age distribution:

- 0.4% aged 0 to 4
- 2.8%aged 5 to 17
- 12.1% aged 18 to 49
- 10.3% aged 50 to 64
- 9.6% aged 65 to 74
- 64.8% aged 75 or over

Our communication methods, including the fact that the survey was online, may have made it harder to reach over-75s. Further work could be done here but there is also plenty of existing evidence which validates our findings. The priorities identified by respondents were the same regardless of age.

Level of sight loss

Of the 350,000 people across the UK who are registered either blind or partially sighted, half fall into each category. Of the 211 survey respondents who stated that they were either blind or partially sighted, half fell into each category.

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We were not able to reach people who had some sight loss but not sufficient to be registered. This represents almost 1.5m people across the UK. We were only able to reach 30 people who fell into this category. Further work could be done to explore the needs of these people.

Gender and ethnicity

63% of people with sight loss are female, 37% are male **[41]**. 66% of our survey respondents were female and 34% were male.

While national data suggests that black and Asian groups are at higher risks of some conditions that affect sight, there do not appear to be publicly available figures on the ethnic profile of people with a CVI/registration. 90.9% of our survey respondents were White, 4.8% Asian, 1.2% Black. Given our small sample, these numbers represent very small numbers of people. They do broadly reflect the percentages of people from different ethnic groups in the 2011 census.

Employment

Over 50% of our survey respondents under the age of 65 were employed in some capacity, and of those 33.2% were in full-time employment. 12.6% of those under 65 described themselves as 'retired'. 28.7% of those under 65 described themselves as 'unemployed'. Of those under 65 who are registered blind (n=87), 29% were employed full-time and 11% part-time. These are much higher figures than the national data for the registered population (for example, **My Voice 2015 [42]**)

Key statistics

Support for sight loss

74% of respondents had accessed support for their sight loss. 17% stated that they had not accessed any support for their sight loss.

Of those who had accessed support, over two-thirds had received some support from a sight loss charity. Over half had received support from a vision rehabilitation worker and nearly 60% had received support from an ophthalmologist. The table below shows the range of support accessed:

If you answered 'yes' to question 11, who was the support from? Tick as many as apply.		
Answer Options	Response Percent	Response Count
Sight loss charity (please specify)	66.5%	133
Ophthalmologist	58.0%	116
Vision rehabilitation worker	52.5%	105
Optician / optometrist	40.5%	81
Eye surgeon or other specialist (please specify)	30.0%	60
GP	25.0%	50
Other (please specify)	17.0%	34
If you were asked to specify your answer, please do so here.		138
answered question		200
skipped question		115

Respondents were also asked to comment on the support they received. The following table shows how far respondents agreed or disagreed with a series of statements about the support they received. The level of agreement was consistent across age, level of sight loss and the age at which people lost their sight.

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If you answered 'yes' to question 11, how far do you agree with these statements about the support that you received?						
Level of agreement						
Answer options	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Response count
I got the support I needed at the right time	15.6%	35.0%	16.7%	22.8%	10.0%	180
I got the support I needed from the right people	21.2%	36.9%	21.8%	15.6%	4.5%	179
I received information about my condition in a way that I could understand and cope with	16.1%	32.8%	17.8%	22.8%	10.6%	180
It was easy to find the right support from the right people	8.8%	21.4%	18.7%	31.3%	19.8%	182

The weighted average for each statement is helpful in understanding how they compare. Scoring 'strongly disagree' as 1 and 'strongly agree' as 5, the weighted averages are below:

- I got the support I needed at the right time: 3.23
- I got the support I needed from the right people: 3.55
- I received information about my condition in a way that I could understand and cope with: 3.21
- It was easy to find the right support from the right people: 2.68.

Priorities for improving the lives of people with sight loss

Respondents were asked to choose their top three priorities from a list of ten. These priorities were broadly consistent across age, level of sight loss and age at which people lost their sight. The top four priorities were:

- more practical support to help people with sight loss live more independently (51.3% of respondents chose this as one of their top three)
- more information about help available and where to go (48.7%)
- greater public understanding of the effects of sight loss (44.1%)
- more emotional support to help people come to terms with their sight loss (39.9%).

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The only difference from these was that people who lost their sight under the age of 25 prioritised access to education and employment higher than emotional support.

The following table gives the detailed figures for the top ten priorities.

Priority	Priority 1	Priority 2	Priority 3	Total
More practical support to help people with sight loss to be more independent	16.8%	16.5%	18.3%	51.3%
More information about help available and where to go	24.8%	16.5%	7.7%	48.7%
Greater public understanding of the effects of sight loss	13.4%	10.6%	20.4%	44.1%
More emotional support to help people come to terms with their sight loss	13.0%	14.8%	12.3%	39.9%
More information about financial benefits for people with sight loss	2.9%	9.7%	6.8%	19.3%
Better information about taking care of your eye health	8.0%	5.5%	4.3%	17.6%
More access to education and employment opportunities	6.7%	6.8%	4.3%	17.6%
More information in the right format for people with sight loss	5.0%	7.6%	3.0%	15.5%
More information on assistive technology	2.5%	5.1%	7.2%	14.7%
More accessible public transport	2.1%	5.5%	6.8%	14.3%
More accessible leisure facilities	0.4%	0.0%	4.3%	4.6%
Other (please specify)	4.2%	1.3%	4.7%	10.1%
Response count	238	236	235	

7.3 Lists

Member Organisations of the Vision Strategy Leadership Group

- Action for Blind People
- British and Irish Orthoptic Society
- College of Optometrists
- A Consultant Ophthalmologist
- Guide Dogs
- HIV and Sensory Impairment Network for Association of Directors of Adult Social Services
- NHS Alliance
- Optical Confederation
- Royal College of General Practitioners
- Royal College of Nursing Ophthalmic Nursing Forum
- Royal College of Ophthalmologists
- Royal National Institute of Blind People
- VISION 2020 UK
- Visionary

Member Organisations of the Country Vision Strategy Implementation Groups

England Vision Strategy Executive Group

- Blind Children UK
- College of Optometrists
- Guide Dogs
- HIV and Sensory Impairment Network for Association of Directors of Adult Social Services
- Local Optometric Committee Support Unit
- Ophthalmic Nurses
- Royal College of Ophthalmologists
- RNIB
- Thomas Pocklington Trust
- UK Vision Strategy
- VISION 2020 UK
- Visionary

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Observers: Department of Health and NHS England

Northern Ireland Vision Strategy Implementation Group

- Department for Communities
- Department of Education
- Department for the Economy
- Department of Health
- Department for Infrastructure Department for Communities
- Guide Dogs (Northern Ireland)
- Health and Social Care Board Inclusive Mobility and Transport Advisory Committee
- The Executive Office RNIB (Northern Ireland)
- UK Vision Strategy

Scottish Vision Strategy Advisory Group

- Blind Children UK (Scotland)
- Counselling and Emotional Support Services Group
- Diabetic Retinopathy Screening
- Guide Dogs (Scotland)
- Macular Society
- North East Sensory Services
- Optometry Scotland
- Royal Blind
- RNIB (Scotland)
- Scottish Association of Visual Impairment Education
- Scottish Eyecare Group
- The Scottish Council on Visual Impairment
- UK Vision Strategy
- VISION 2020 UK
- A Vision Ambassador
- Visionary
- Visual Impairment Network Children Young People

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Wales Vision Strategy Implementation Group

- Action on Hearing Loss Cymru
- British and Irish Orthoptic Society
- Cardiff Institute for the Blind
- Deafblind Cymru
- Guide Dogs Cymru
- North Wales Society for the Blind
- Optometry Wales
- RNIB Cymru
- Royal College of Nursing Wales
- Sense Cymru
- Sight Cymru
- Wales Council of the Blind
- Vision Support
- Welsh Local Government Association
- Wales Optometric Postgraduate Education Centre at Cardiff University School of Optometry and Vision Sciences
- Welsh Government
- Welsh Rehabilitation Officers Forum

7.4 Glossary and definitions

An asset-based approach involves mobilising the skills and knowledge of individuals and the connections and resources within communities and organisations, rather than focusing on problems and deficits. **A deficit-based approach** tends to focus on identifying the problems, defines individuals in negative terms, and disregards what is positive and works well.

Certification of Blindness or Defective Vision (BP1): the equivalent form in Scotland to the CVI in England, Wales and Northern Ireland (see below).

Certificate of Vision Impairment (CVI): the form used in England, Wales and Northern Ireland to certify a patient's eligibility to be registered with their local authority, either as sight impaired (partial sight) or severely sight impaired (blind). It can only be signed by a consultant ophthalmologist.

Clinical Commissioning Groups (CCGs) were created following the Health and Social Care Act in 2012, and replaced Primary Care Trusts on 1 April 2013. CCGs are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. There are now 209 CCGs in England

Diabetic retinopathy: damage to the blood vessels at the back of the eye caused by fluctuating blood sugar levels.

Glaucoma: a group of disorders often associated with a raised internal eye pressure which can damage the optic nerve at the back of the eye and so result in sight loss.

Habilitation: the acquisition of mobility, orientation and other independent living skills in relation to children and young people born with vision impairment or who acquire it during childhood. A qualified habilitation specialist is the lead specialist in delivering this training. He/she is responsible for assessing the habilitation needs of the child and all aspects of the training programme. They work with the young person, their family, and other professionals, such as specially qualified teachers to ensure a joined up approach.

Macular degeneration: an eye condition, usually age-related, which involves deterioration of the part of the back of the eye responsible for the sharp, central vision, needed to read or drive, for example.

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Nurse practitioners: registered nurses (RNs) who have completed advanced education (a minimum of a master's degree) and training in the diagnosis and management of common medical conditions, including chronic illnesses. Nurse practitioners provide a broad range of health care services. They provide some of the same care provided by physicians and maintain close working relationships with physicians. An NP can serve as a patient's regular health care provider.

Occupational therapists: provide support to people whose health prevents them doing the activities that matter to them

Ophthalmic medical practitioner: an ophthalmologist, who can also test sight and issue spectacle and contact lens prescriptions in the same way as optometrists in high street practices.

Ophthalmic nurse: has a general nursing qualification plus specialist training in eye care, assists in surgery and manages, amongst others, patients with glaucoma, cataract, low vision and other eye conditions.

Ophthalmic nurse prescriber: an ophthalmic nurse who has successfully completed studies so they can prescribe medication.

Ophthalmologist: a medically qualified doctor, with postgraduate specialty training in medical and surgical ophthalmology, who examines, diagnoses and treats diseases of the eye; and also prescribes medicine and performs surgery. Typically works in a hospital although may also work in community settings.

Optician (dispensing optician): qualified to advise on, dispense and supply spectacles and low vision aids; in addition, they are able to offer advice on aspects of eye care and vision. Some dispensing opticians hold additional qualifications, enabling them to fit and dispense contact lenses.

Optometrist (ophthalmic optician): qualified to perform sight tests or eye examinations, gives advice on visual problems, and prescribes and dispenses spectacles, contact lenses and other visual aids.

Optometrist independent prescriber: an optometrist who holds additional qualifications to enable them to prescribe medication that may be required for an eye condition.

Orthoptist: qualified to diagnose, treat and manage defects of vision, binocular vision and eye movements including strabismus in both adults and children. They work mainly within the NHS. They have expertise in working with children and with

patients who have neurological conditions including stroke and acquired brain injury. Orthoptists are involved in education with children and people with learning disabilities and following additional training, they also work in glaucoma and cataract clinics.

Primary care: the first point of contact for a person with a healthcare provider, for eye health problems usually an optician, optometrists or GP. Generally, this contact takes place in a high street or community setting, such as an optician's premises or GP surgery.

Public Health: this concerns helping populations stay healthy, and protecting them from threats to their health. It includes promoting healthier choices, prevention of ill health and impairment and minimising the risk and impact of illness.

Public sector: services supported by the government.

Qualified Teacher of the Visually Impaired (QTVIs): have extra training in working with children with visual impairment, and work in special and mainstream schools or within visual impairment service teams.

Rehabilitation: vision impairment rehabilitation is a form of reablement for people who are blind or who experience sight loss, to enable independent living. It involves specific interventions around acquiring new skills and is often accompanied by structured emotional support. Rehabilitation is time limited but not time prescribed.

Rehabilitation officer for vision impairment (also known as a rehabilitation worker): qualified to provide specialist assessments, rehabilitation interventions, training and advice to people with sight loss.

Secondary care: a term used to indicate treatment by specialists to whom a patient has been referred by primary care providers. Secondary care is generally hospital-based.

Sight impaired/severely sight impaired: these terms replaced partially sighted and blind and are usually used when referring to registration or certification in England, Wales and Northern Ireland.

Sight test: sight tests are primarily performed by community optometrists, to check vision (and associated problems) and determine whether or not the person needs spectacles. It is a legal requirement that whenever a sight test is performed the practitioner examines the internal and external health of the eyes. If necessary

glasses, contact lenses or low vision aids may be prescribed. If any abnormalities or concerns about the health of the eye are detected, they may be managed by the optometrist or by referral for a more specialist opinion from an ophthalmologist for example.

Specialist nurses: are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases. They provide direct patient care and can play a vital role in educating patients on how best to manage their symptoms, as well as offering support following diagnosis.

Tertiary care: a term used for the provision of highly specialised consultative services, usually involving expert investigation or treatment.

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