







# Vision Ahead: Report on Improving the Care and Support of Blind, Partially Sighted and Visually Impaired People in Wiltshire

30<sup>th</sup> April 2013



<u>Contents</u>	<u>Page</u>
Background to "Vision Ahead"	3
The role of Alder	3
Aims and scope of "Vision Ahead"	4
Approach to "Vision Ahead"	5
National work that helped to inform us	6
Previous Wiltshire work we built on	7
Workshop 1: How things are now	8
Workshop 2: What we ideally need	11
Data: To validate/inform workshops 1 and 2	13
Workshop 3: What we can do better and how	22
Recommendations - Raising awareness and improving understanding of sight loss	24
Recommendations - Achieving earlier diagnosis and rapid access to care and support	27
Recommendations - Supporting people to live better with their long term sight loss	33
Recommendations - Relevant to awareness raising, early diagnosis and living well with long term sight loss	45
List of Annexes	48



## **Background to "Vision Ahead"**

In 2009-10 Wiltshire undertook a consultative project to help it identify how older people could be supported better. The project started with an "Open Space" event and was followed by 5 workshops that were attended by older people who were customers, carers, social care staff (including practitioners), NHS staff (including practitioners), voluntary sector representatives and other stakeholders. The aim was to "co-produce" an assessment of current services and recommend how they could be improved.

This process was facilitated by Dan Short for the Department of Health Care Services Efficiency Delivery (CSED) programme and it was very successful. It provided the foundations for, created the impetus for and built the relationships/consensus necessary to implement the new "Help to Live at Home" approach. This approach is now being used across Wiltshire and increasingly being recognised across England as "good practice".

In the summer of 2012 the Wiltshire and Swindon User Network (WSUN), Wiltshire Involvement Network (WIN) and Wiltshire Council decided they wanted to sponsor something similar for people who are blind, partially sighted or visually impaired. They hoped that a similar "co-production" process could help create the conditions for improvement across the system for caring and supporting people who live with sight loss. Notably they wanted to:

- Involve as many stakeholders as possible,
- Foster an environment of trust and openness,
- Gain consensus that things need to and can improve,
- Develop a shared vision for the future, and

• Recommend the first steps (bottom up/ top down) needed to create the momentum necessary for real improvement.

From the start there was recognition by the sponsors that the Vision Ahead project needed to be seen in a local and a national context and more specifically to harness momentum from:

- Increased national and international recognition about the need to reduce avoidable sight loss and improve support for blind and partially sighted people. This is evidenced by the *UK Vision Strategy 2008* first developed in response to the World Health Assembly VISION2020 resolution and refreshed 2012.
- The recent series of initiatives to involve blind and partially sighted people living in Wiltshire in processes that aimed to identify how support for blind and partially sighted people living in Wiltshire could be improved including the Wiltshire Vision Strategy Action Group (WVSAG).

#### The Role of Alder

Following a tender process Alder was employed as an independent and impartial external facilitator for the process. Alder was well placed for this role as it:

- Exists to <u>help</u> social care, housing and health organisations better meet the care and support needs of their local populations within available resources with a customer centric approach.
- Had previously worked with Wiltshire Council to help it work in partnership with the NHS to improve the older persons' care and support pathway when the Alder represented the Department of Health Care Services Efficiency Delivery (CSED) Programme in 2010.



## Aims and Scope of "Vision Ahead"

The <u>stated aim</u> in the project brief/scope document dated 28th September 2012 was that:

"Wiltshire is committed to transforming how it supports people with sensory impairment(s) and it wants this transformation to be coproduced by customers and stakeholders.

Therefore, it was agreed, in July 2012, that the partnership of:

- Wiltshire Involvement Network (WIN),
- · Wiltshire & Swindon Users Network (WSUN), and
- Wiltshire Council.

Would, together, focus on visual impairment/loss, and work on a project to produce recommendations on improving the care and support of blind, partially sighted and visually impaired people of Wiltshire.

In recognition of 'Hearing Impairment' and 'Big 'D' Deaf', it is hoped that there will be some work in the near future to embrace these two categories of sensory impairment'.

The <u>stated scope</u> of the approach for the project was that it <u>was</u> <u>about</u>:

√ being aspirational

- ✓ finding out how things are now
- ✓ defining what would be better
- ✓ giving a 'voice of the customer'

Ultimately, the end point was to give evidence showing a need for change and provide a list of recommendations for further action

The stated scope of the project was clear that it was not about:

- x designing in detail
- x deploying/implementing the change
- x commissioning

Though all of these could possibly follow - resulting in changing the way care and services are commissioned in future. In short; the project was to co-produce recommendations for decision takers to consider, rather than make decisions.

#### **Next Steps:**

James Cawley (Wiltshire Council, Service Director – Adult Care and Housing Strategy) committed that at the end of the project:

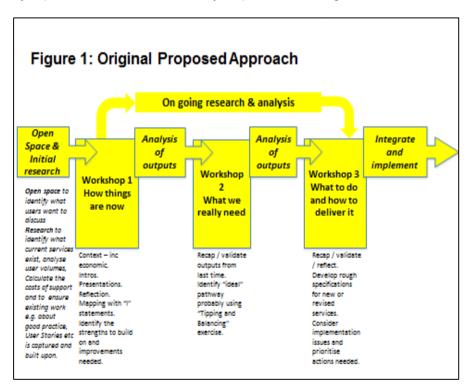
"A final list of recommendations will be presented to the Health and Well-Being Board, in the first instance, in June 2013".

To ensure that the momentum built up by this project is maintained WSUN has committed to holding an update event by the end of 2013, at which implementation progress will be reported.

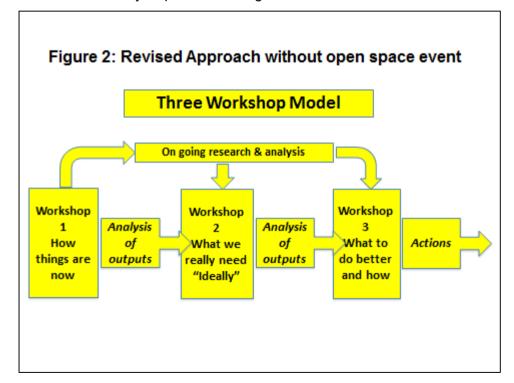


## **Approach to "Vision Ahead"**

The planned method was for an open space event followed by just three (as opposed to the normal recommended five) stakeholder workshops. As always, the whole process was to be underpinned by a parallel research and analysis process see figure 1 below:



Unfortunately, take up for the open space event was considered too low to be viable/robust and so it was cancelled and the method was revised (as follows) to comprise just three workshops and a parallel research and analysis process see figure 2 below.





## National work that helped inform us

The Vision Ahead Process was informed by existing national research that was summarised for participants and shared with them in advance of Workshop 1. The main learning points from the research were that:

#### Who is living with sight loss?

Almost 2 million people in the UK are living with sight loss. Not surprisingly, although sight loss can affect all ages, as people age the incidence of sight loss increases and more women experience sight loss than men:

- 1 in 5 people aged 75 and over are living with sight loss
- 1 in 2 over aged 90 and over are living with sight loss
- Nearly two-thirds of people living with sight loss are women.

<u>Learning</u>: The Vision Ahead project needs to anticipate that as the County's population ages in the next 20 years it can expect demand for services specifically for people with sight loss to increase rapidly and recommendations should take this into account.

Perhaps less well known is that black and minority ethnic communities are at greater risk of sight loss and adults with learning disability are 10 times more likely to have sight loss than the general population.

<u>Learning</u>: The Vision Ahead recommendations need to take account of the need to be both culturally sensitive and accessible for people with learning disabilities. "One size to fit all" is unlikely to be the answer.

#### Who is registered as blind/partially sighted?

Registration is recognised as being important as access to key benefits and some support can be conditional on being registered as blind/partially sighted. However, national data shows that the majority of people who live with sight loss are not registered i.e. only 360,000 people are registered as blind/partially sighted. This is estimated to represent just 1 in every 6 who could be.

Data from the <u>Wiltshire and Swindon Intelligence Network</u> (2012) confirms Wiltshire mirrors the national position as it is estimated that up to 14,000 people in Wiltshire live with sight loss, but only 3,125 are currently registered as being blind or partially sighted.

<u>Learning</u>: The Vision Ahead recommendations need to consider how to increase the proportion of eligible people registered as blind/partially sighted.

#### How preventable is sight loss?

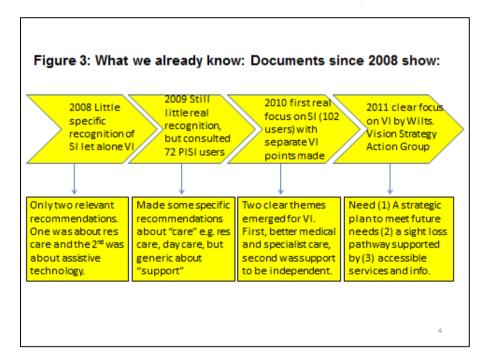
Many older people are needlessly living with sight loss because almost 2/3<sup>rds</sup> of sight loss in older people is caused by refractive error or cataracts. Both of these conditions can be diagnosed by a simple eye test and often the person's sight could be improved by the correct glasses/surgery. In fact national data indicates that over 50% of sight loss overall (in all ages) could be avoided.

<u>Learning</u>: The Vision Ahead recommendations need to reflect that <u>prevention and early intervention</u> can make a big difference to people's lives and consider how people can be made more aware how to care for their sight better.



## Previous Wiltshire work we built on

Since 2008 when the UK Vision Strategy 2008-13 was launched, Wiltshire has been increasing its strategic focus on improving support for people who live with sight loss and striving to better include blind, partially sighted and visually impaired people in service planning and design. A selection of key documents since 2008 demonstrates this. These are summarised at fig 3 below:



Note: VI = Visual impairment, PI = Physical impairment and SI = Sensory impairment

In particular, the Wiltshire Vision Strategy Action Group (WVSAG) recommended in 2011 that:

- The Joint Strategic Needs Analysis needs to ensure the needs of blind/partially sighted and visually impaired people are clearly identified and planned for.
- A clear "care and support pathway" is needed. It should incl:
  - Prevention,
  - · Early intervention at the time sight is lost, and
  - Long-term support e.g. to help people adapt to long term situation.
- <u>ALL</u> services that support the pathway need to be made accessible. Specifically:
  - Expand rehabilitation services so there are no waiting lists,
  - Ensure enough Rehabilitation Officers for Visual Impairments (ROVI) are in post,
  - Clarify referral processes to ROVIs and to other clinical and support services,
  - Employ an eye care liaison officer at Salisbury District Hospital, and
  - Improve the information available across the board.

The participants in the Vision Ahead project agreed that it was important to take this important body of existing work into account and former members of WVSAG were invited to be are part of Vision Ahead to ensure continuity.



## Workshop 1: How things are now

#### Introduction

Workshop 1 was held at the Devizes Corn Exchange on 7<sup>th</sup> November 2012 from 10.15 a.m. to 3.00 p.m. It was attended by 56 people including:

- 18 Customers or carers
- 14 Council or NHS staff
- 13 WSUN/WIN staff
- 7 Care and support provider staff incl. Salisbury DC
- 4 Representatives of voluntary sector organisations

#### The main aims of workshop 1 were to:

- Bring the knowledge of all participants up to date in terms of national research about sight loss and local work to date.
- Allow participants to state their hopes about the Vision Ahead process and surface and share any fears they had.
- Share experiences of the current care and support system for blind, partially sighted and visually impaired people in Wiltshire and use these to identify:
  - Features of support that were identified as good so the design for the future can build these good features in,
  - Strengths about the current care and support system to build on, and
  - Opportunities for improvement where current experience falls short of expectations.

#### **Hopes and Fears**

Annex 1 gives a full record of the "hopes and fears" but in summary the main hopes were that as well as being enjoyable:

- · All participants feel involved and listened to
- Everyone who is involved learns from the process
- The project leads to "real" improvements

The main fears were that:

- The project might get bogged down by jargon
- Important changes recommended might not get implemented

#### **Features of Good Support**

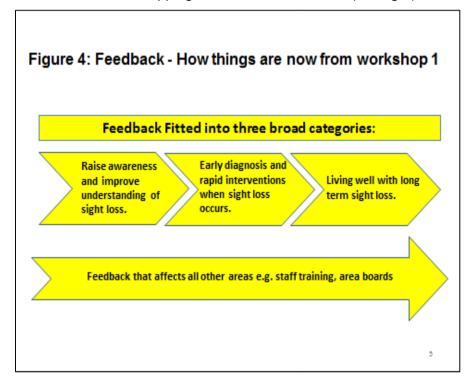
Annex 2 gives a full record of the "features associated with good experiences of support", but in summary the keys ones were that (1) there is accurate and up to date accessible information about what is available, how to self-help and how to access support and (2) when it is needed the care and support provided is:

- Promptly available.
- Tailored to meet individual needs,
- · Delivered by well trained staff/volunteers, and
- Takes account of the needs of carers as well as the customer/ patient.



#### Strengths and opportunities to improve:

Although the feedback on strengths and opportunities to improve was wide and varied it broadly fitted into three key areas with some feedback overlapping all three of these areas (see fig 4):



Although Annex 3 records the full feedback given about current strengths and opportunities to improve the main points are summarised here.

They show that while many strengths exist and can be built on; there are still many areas where care and support could improve.

The keys points about "Raising awareness and improving understanding of sight loss" were praise for:

- An organisation called GROW for providing good community information, and
- Six week "Moving On" clinics for people who have recently experienced sight loss.

While awareness could be raised and understanding of sight loss could be improved further if Wiltshire:

- Started the education process earlier e.g. in schools
- Emulated other successful public awareness campaigns e.g. for strokes/ dementia
- Had a "one stop" shop for all information/ advice about <u>ALL</u> disability services so all disabled people including those with sight loss would know where to access information at all times and be confident it was accurate and up to date.

The keys points about achieving "Early diagnosis and rapid access to support" were praise for:

- The Hearing and Vision Team e.g. for providing a knowledgeable key worker for individual customers,
- Key improvements at Salisbury Hospital e.g. the "Meet and Greet" service, and



• High street opticians e.g. as they are easily available and "refer people on" promptly for specialist support when they believe it to be necessary.

While the chances for earlier diagnosis and the speed of access to support after diagnosis could be increased if in Wiltshire the:

- Percentage of people registered as blind/partially sighted increased as a share of those eligible to be registered,
- · Consistency of support from hospitals improved,
- Waiting times for support from the Hearing and Vision Team reduced, and
- General Practitioners and Pharmacies tailored their services better to meet the needs of people with sight loss.

The key points about "Living well with long term sight loss" were praise for:

- Talking newspapers and libraries in Wiltshire as these help to keep blind, partially sighted and visually impaired people well informed,
- Telecare as it was seen as a flexible and low cost way of helping people to be more independent and to stay safe,
- Travel training by various organisations as the ability and confidence to travel independently empowers people, and
- Numerous existing support groups in Wiltshire that help people maintain their independence and help to protect against social isolation.

# But, people could be helped to live with their long term sight loss even more effectively if:

- Some support was more flexible, as some still has a "one size fits all" approach,
- Some support staff/ volunteers had better skills/ knowledge as, at present, some lack awareness or sensitivity to the needs of people who are visually impaired,
- The capacity of some highly valued services were to increase as some services currently have quite long waiting lists, and
- Access to public places and transport for people with sight loss was improved as currently poor design and environmental factors can restrict what people with visual impairments are able to do.

In terms of <u>issues that overlap with the three categories of</u> **issues above** participants at Workshop 1 identified that:

- Local area boards could do much more locally to promote awareness, fund initiatives for early diagnosis and tackle local things that restrict the independence of people with visual impairments e.g. unsafe road crossings and uneven pavements,
- Staff training affects across all areas because well trained staff would pass on information that helped raise awareness, would advise people better when they may need to seek more specialist advice and would tailor the support they provided better to people living with long-term sight loss.



## Workshop 2: What we ideally need

#### **Introduction**

Workshop 2 was held at the Devizes Corn Exchange on 13<sup>th</sup> December 2012 from 10.15 a.m. to 3.00 p.m. It was attended by 44 people including:

- 15 Customers or carers
- 15 WSUN/WIN staff
- 8 Council or NHS staff
- 4 Representatives of voluntary sector organisations
- 2 Care and support provider staff

#### The main aims of workshop 2 were to:

- 1. Define what an "Ideal" system of care and support would be like if it were able to:
  - Achieve perfect public awareness/understanding of visual impairment, how to prevent it and how to support people with visual impairments?
  - Ensure <u>all</u> people with a visual impairment were identified, diagnosed and treated at the earliest possible stage in their sight loss journey?
  - Support <u>all</u> people with long term sight loss to have as full a life as they wanted to have?
- 2. Identify how close the current system of care and support is to the "Ideal" defined and to highlight specific gaps.

#### The "Ideal"

Annex 4 records the "Ideal" system of support for blind, partially sighted and visually impaired people living in Wiltshire defined by the participants at Workshop 2, but in summary the **main ideal features** were a world where:

- Having a visual impairment is understood, respected, acknowledged by all in society and where no one feels stigma or is reluctant to ask for help.
- Everyone understands how to prevent avoidable sight loss where the identification of problems and referral to hospital or for other assistance is consistently early and timely.
- The ethos underpinning all support is to "enable" people with sight loss to live the life **they** want to live.
- All support is personalised i.e. tailored to individual needs and adequately resourced.

#### The "Gaps"

Annex 5 gives a full record of all the gaps between the current system and the "Ideal World" described during Workshop 2, but in summary the main gaps were as follows:

#### Gaps Re: Raising awareness and increasing independence:

Participants reported that awareness and understanding was a long way away from the "Ideal". Notably there is:

- No effective media campaign promoting awareness.
- Not enough good quality training of front line care and/or support staff.



- No "one stop shop" for information in accessible formats.
- Very little targeted awareness training with other groups e.g. school children, new car drivers and bus drivers.

# Gaps Re: Early diagnosis and ensuring rapid access to support:

Participants reported that prevention, early diagnosis and rapid access to support was very rarely in line with the "Ideal". Notably there is a need for:

- Eye specialist(s) to be appointed on to the Wiltshire Clinical Commissioning Group.
- Proof of the financial case for prevention and early intervention to be presented to decision takers.
- Regular screening for all to identify sight loss early e.g. as part, for example, of annual health checks.
- Support so GPs know more about sight loss.
- Immediate access to key services. Current waiting times are too long. Second hospital appointments are a particular issue.
- A designated Eye Clinic Liaison Officer(s) (ECLO) at each hospital with an "Eye Clinic".
- Much faster registration for sight impaired or severely sight impaired people.

#### **Gaps Re: Living well with long-term sight loss:**

Participants reported that support to live well with long-term sight loss has improved in recent years, and this is a very positive thing, but to achieve the "Ideal" there is still a need for:

- Support services to be more co-ordinated and to share information better
- A "named link support worker" to help individuals find/use services e.g. the equivalent of a dementia navigator.
- Peer support, buddy and befriending schemes to develop further.
- An increase in rehabilitation services to support people to become more independent over time.
- Better support to use assistive and other technology that supports independence.
- Better access to guide dogs; notably shorter waiting times and better access for children.
- Shops, Leisure, Libraries and other services to be more accessible.
- Transport to be made more accessible for people with visual impairments.
- Better support to get and keep employment.
- · Better support to claim benefits.



## Data to validate/inform workshops 1 and 2

Every effort was made to ensure that the Vision Ahead members were a representative sample of customers and other stakeholders

However, to ensure, the project was informed by as full a range of views as possible feedback from workshops 1 and 2 was validated against:

- Feedback from the "Wiltshire Voices" consultation project,
- The UK Vision Strategy Refresh 2012, and
- Data obtained by the Vision Ahead Data Group.

#### **Feedback from Wiltshire Voices:**

Wiltshire Voices began in May 2012 and concluded in February 2013. It was a far wider consultation process than Vision Ahead as in included a far wider range of people than Vision Ahead<sup>1</sup>.

Of the 12 sub groups for 'Wiltshire Voices', one was a forum of 40 people who are blind or partially sighted. This group was directly relevant to Vision Ahead; so the feedback/views expressed at group workshops or at individual interviews were reviewed and compared to the feedback/views expressed at Vision Ahead workshops 1 and 2.

#### **Similarities with Vision Ahead:**

Much of the feedback from Wiltshire Voices was consistent with that from Vision Ahead workshops 1 and 2. For example, like Vision Ahead Wiltshire Voices emphasised the need:

- For information and emotional support straight after diagnosis e.g. Vision Ahead feedback about the need for an Eve Clinic Liaison Officer was reinforced.
- For advice on how to be registered as severely sight impaired (blind) or sight impaired (partially sighted) as this is key to accessing a wider range of support e.g. consistent with Vision Ahead feedback about raising awareness about help available and how to access it
- For support to live with long term sight loss was stressed e.g. one person said "most of the modern world does not have a clue what people with disabilities go through".
   Examples of the types of support needed were:
  - Practical support e.g. to fill in forms that cannot be read and support to socialise, meet peers etc. so that the risk of isolation is reduced.
  - Small changes in service design and in how others behave that would make a big difference e.g. medication labels need to be in large, black on yellow print and cashpoints need to "talk" to users, and
  - Arrangements that would make travel easier and safer e.g. by making buses and trains more accessible and by ensuring pavements are well maintained and free of obstructions.

<sup>&</sup>lt;sup>1</sup> More details about Wiltshire Voices can be found at http://www.wiltshire.gov.uk/communityandliving/wiltshirevoices.htm



#### **Differences compared with Vision Ahead:**

There were no absolute differences, but some things were emphasised differently. Most notably the:

- Economic and psychological impact of sight loss was more passionately explained in Wiltshire Voices,
- Frustration that many employers are not willing to give people with sight loss a chance was more heartfelt in Wiltshire Voices, and
- Value of technology and its sometimes prohibitive costs was more clearly explained in Wiltshire Voices.

#### **Learning:**

Although there were a few differences in emphasis the feedback and views expressed through Wiltshire Voices validated the feedback and views from Vision Ahead Workshops 1 and 2 and were consistent with earlier work such as the Wiltshire Vision Strategy Action Group.



#### **The UK Vision Strategy Refresh 2012:**

The UK Vision Strategy seeks to transform the UK's eye health, eye care and sight loss services.

It is a UK wide initiative in response to the World Health Assembly VISION2020 resolution to reduce avoidable blindness by the year 2020 and improve support and services for blind and partially sighted people.

The UK Vision Strategy attempts to respond to perceived:

- Shortfalls in the UK's eye health and sight loss services,
- Exclusions of blind and partially sighted people from opportunities available to others, and
- Widespread ignorance amongst the general public about how to maintain eye health.

The UK Vision Strategy has three priorities and each priority is associated with a five year aim.

A comparison of these priorities with the Wiltshire Vision Ahead priorities (Table 1 below) found that whilst the Wiltshire priorities are not identical because they reflect local circumstances they do cover very similar ground i.e. we concluded that The UK Vision Strategy validates feedback from Workshop 1 and vice versa.

<u>Table 1: Comparison of UK Vision Strategy with Vision Ahead</u>

UK Vision Strategy <sup>2</sup> :	Similar to Vision Ahead Priority:
1. Improving the eye health of the people of the UK. <u>Five-year aim</u> : To raise awareness and understanding of eye health and ensure the early detection.	To "Raise awareness and improve understanding of sight loss and how to prevent it."
2. Eliminating avoidable sight loss and delivering excellent support for people with sight loss. Five-year aim: To improve the coordination, integration, reach and effectiveness of eye care and support services.	To "Ensure early diagnosis and rapid interventions when sight loss occurs."
3. Inclusion, participation and independence for people with sight loss. <b>Five-year aim:</b> To improve the attitudes, awareness and actions of service providers, employers and the public to increase independence, control and choice.	To "Help people live well with long-term sight loss."

<sup>2</sup> Source: Adapted from UK Vision Strategy Refresh 2012



#### **Vision Ahead Data Group:**

#### What we did:

In parallel to the 3 workshops a data group was formed to find out what data was available about the current support for blind, partially sighted and visually impaired. We wanted data to (a) inform debate at the workshops and (b) to validate the perceptions and views outlined at the workshops. This group:

- Obtained 2012 population data for Wiltshire from the Institute of Public Care POPPI and PANSI data available from Oxford Brookes University.
- Asked Wiltshire Council as the body responsible for adult social care for information about the types of social care/ support available and a profile of people the with sight loss who it supports.
- Asked NHS Wiltshire CCG as the body that funds treatment for eye conditions we sought information about patient numbers, activity levels and costs related to Ophthalmology.
- Asked Haine and Smith Opticians (a large regional optician that operates mainly in Wiltshire) for information about what services Opticians typically provide and a profile of the people registered with them.

#### **Population Data:**

In 2012 the population of Wiltshire was 477,000. The population is projected to grow steadily in the next few years and the profile will age (See table 2 below). The data shows the numbers in the population that will be aged 65 plus will increase from 90,400 in 2012 to 111,900 in 2020. This represents an increase from 19%

to 22.3% of the Wiltshire population while the younger adults population (18 to 64) is forecast to remain at around 280,000 over the same period.

**Table 2: WILTSHIRE POPULATION PROJECTIONS** 

Age Bands	2012	2014	2016	2018	2020
People aged 65-69	28,100	30,400	30,800	28,700	28,400
People aged 70-74	20,500	22,300	24,800	28,700	29,600
People aged 75-79	16,700	17,800	18,300	19,700	21,700
People aged 80-84	12,500	13,000	13,700	14,600	15,500
People aged 85-89	8,000	8,300	8,800	9,400	10,000
People aged 90 Plus	4,600	5,100	5,600	6,100	6,700
Total pop'n 65 plus	90,400	96,900	102,000	107,200	111,900
People aged 18-24	35,600	33,800	32,700	31,800	30,800
People aged 25-34	52,100	53,300	53,900	53,800	53,700
People aged 35-44	64,300	61,100	58,900	57,700	57,900
People aged 45-54	71,500	72,900	73,600	72,800	70,000
People aged 55-64	59,100	59,500	61,800	64,800	68,300
Total pop'n aged 18-64	282,600	280,600	280,900	280,900	280,700
Total pop'n aged 0-17	104,000	105,600	106,400	107,500	109,500
Total pop'n - All ages	477,000	483,100	489,300	495,600	502,100

Source: POPPI/PANSI data from IPC Oxford Brookes University.

**Learning:** Since sight loss increases with age, this data confirms that demand for care and support for blind, partially sighted and visually impaired people is likely to increase in the next few years unless effective prevention and early intervention measure can be put in place i.e. it validates the emphasis put on prevention by the members of the "Vision Ahead" group.



#### **Adult Social Care (ASC) Data:**

Customer records show that in the year to 31<sup>st</sup> October 2012 ASC supported 365 people whose primary or secondary support need was visual impairment or who had a chronic sickness or disability related to their eyesight.

365 is only 0.1% of Wiltshire's adult population and may seem very low. However, it should be noted that 365 will not account for all the people with sight loss that ASC supports as it only includes people where sight loss is the primary or secondary reason for support i.e. ASC will support other people who have experienced some sight loss particularly in its older peoples and learning disability customer groups, but in many cases sight loss will not be the recorded main reason for that support.

#### What do we know about these 365 people?

- 240 (66%) are female, and 125 (34%) are male i.e. female customers outnumber male customers by 2 to 1.
- Only 88 (24%) are aged under 65. 201 (55%) are aged over 81 i.e. three quarters of customers are older people.
- Only 107 (29%) were 1<sup>st</sup> supported by ASC before they were 60 whereas 157 (43%) were 1<sup>st</sup> supported post 81.
- In 301 (82.5%) of the cases, sight loss or dual sensory loss is the primary reason for support.
- The only expenditure known to exclusively support sight loss is £170,000 of the hearing and vision team's budget. This includes staff costs and equipment supplied.

This data tends to reinforce the age related nature of the majority of sight loss and if we put this together with data about half of all sight loss being preventable, the value of effective measures to prevent sight loss and visual impairments is clear.

#### How are blind and partially sighted people supported?

339 or 93% of the 365 ASC customers live in their own home or that of a family/ friend or other informal carer. Only 7% live in residential, nursing or other specialist settings. We also know that national data indicates that:

- Only around 3,125 people in Wiltshire are registered as blind/ partially sighted, while
- Wiltshire and Swindon Intelligence Network (2012) estimates that up to 14,000 people in Wiltshire are blind or partially sighted.

When you put this data together it is clear that <u>the majority of people with sight loss must live in the community</u> rather than in residential, nursing or other specialist settings.

**<u>Learning:</u>** The ASC data confirms the views expressed by "Vision Ahead" group members that it is important to:

- Make information about eye care and what to do when worried about your sight easily available to the public,
- Make communities friendly and accessible so that people who are blind, partially sighted or visually impaired can be as independent as possible,
- Be able to deliver specialist visual impairment services effectively into community settings, and
- Recognise and support the role of informal carers who support blind, partially sighted and visually impaired people, often for no cost, on a day to day basis.



#### NHS Wiltshire Clinical Commissioning Group Data:

Table 3 below shows that in the year to 31<sup>st</sup> October 2012 3,464 patients attended 5,083 Ophthalmology related in-patient admissions in Wiltshire with an approximate cost of £3.75m<sup>3</sup>.

Table 3: In Patient			Patient
Admissions	Activity	PBR Cost	Count
Ophthalmology	5,083	£3,775,217	3,464

3,464 patients represent around 1% of the adult population of Wiltshire (373,000) in 2012. Table 4 below shows that in the year to 31<sup>st</sup> October 2012 20,118 patients attended 47,031 Ophthalmology out-patient attendances in Wiltshire. These cost around £4.5m based on payment by results (PBR) tariffs.

Table 4: Out Patient Attendance	Type	Activity	PBR Cost	Patient Count
Ophthalmology	First	14,349	£1,775,305	12,112
Ophthalmology	Follow up	32,682	£2,709,421	13,753
	Total	47,031	£4,484,726	20,118 <sup>4</sup>

Ophthalmology services therefore has contact with 23,582 people in 2011-12. This represents 6% of Wiltshire's adult population.

<u>Analysis</u>: NHS Wiltshire's data indicates it had contact with many more people with visual impairments in 2011-12 than Adult Social Care (ASC) did and this conclusion would remain true even if the:

<sup>3</sup> Relates to LL eye care NOT just that for people with long term sight loss.

- NHS count includes some people from neighbouring counties who use a Wiltshire Hospital
- Overlaps between the two lists could be identified and taken into account, and
- ASC data undercounts VI customers as the data interrogation is based on the primary or secondary care needs only. Therefore it only counts people with a primary or a secondary care need recorded as visual impairment.

It is also true that in terms of a "Visual Impairment Care and Support Pathway" most people will have NHS contact e.g. for diagnosis and for initial treatment/care related to their loss of sight before being referred to ASC for an assessment, rehabilitation support, equipment or help with day to day living.

Learning: When prioritising recommendations and considering cost effectiveness Vision Ahead group members need to have regard for the relative number of people with visual impairments who will benefit and the relative position of different recommendations on the "care and support pathway". For example, early contact with the NHS will impact on more people and potentially have a more positive impact on customers than, for example, recommendations about residential or nursing care because very few visually impaired people live in specialist settings and by the time they reach such settings their needs are high and hard to "manage down".

That said, we know that the majority of visually impaired people live in the community with little or no support. So recommendations that help visually impaired people live better with their sight loss at home and in the local community probably benefit the most people.

<sup>&</sup>lt;sup>4</sup> The total patient count is lower than the sum of the patient count for first and follow up attendances, as some patients had a first and a follow up attendance.



#### **Opticians Data:**

#### Who attends opticians and why?

"Optics at a Glance" is an annual publication by the Optical Confederation<sup>5</sup>. The 2010-11 publication was the most up to date one available when we went to press. It states that:

- 68% of adults in England wear spectacles or have contact lenses i.e. it is reasonable to assume therefore that more than 68% of adults are registered with an optician, and
- In 2010-11 17.4m sight tests were carried out by opticians in England. This represents nearly 1 test for every 3 people who live in England (53.585 million in 2012<sup>6</sup>)

#### Learning:

It seems that people within the scope of Vision Ahead i.e. people with sight loss or at risk of sight loss are far more likely to see an optician than to visit a hospital or have support from adult social care.

Clearly people may also visit their GP, but where sight loss was suspected the GP is likely to refer the patient to either an optician or a hospital eye clinic. This is significant because it means that if the people at risk see their local optician for sight tests then:

• Early detection of sight loss should be possible, and

• Opticians would be a good channel to communicate education and awareness raising materials.

#### The risk of over reliance on opticians:

At workshops 1 and 2 Vision Ahead group members agreed that while opticians do see a lot of people and their role, location and expertise are all strengths that could be built on, but it was complacent to assume that no improvement was possible.

The groups reasoning was that many of the people who most need to attend and who most need to increase their awareness of prevention i.e. young adults, do not register with/visit an optician until they "notice" their sight has deteriorated. Often this is too late and opportunities to intervene early and limit/correct sight loss have been missed. Hence, the Vision Ahead group wanted to:

- Prioritise public awareness raising so young adults are more likely to register with an optician and have sight tests every two years,
- Ensure some awareness raising focused on hard to reach groups (and included "in reach" into youth services), to increase coverage across social, racial and other boundaries in the population, and
- Make the screening of children compulsory in schools so that children's opportunity to have their sight tested is not dependent on having a responsible and knowledgeable parent who recognises the value of regular sight tests.

We were keen to test whether this feedback was valid and contacted Haine and Smith Opticians to see if the profile of people registered with them confirmed or contradicted the feedback from the Vision Ahead group members.

<sup>&</sup>lt;sup>5</sup> http://www.opticalconfederation.org.uk/downloads/keystatistics/Optics%20at%20a%20Glance%202011.pdf

<sup>&</sup>lt;sup>6</sup> From Poppi and Pansi by Institute of Public Care at Oxford Brookes University <a href="http://www.poppi.org.uk/">http://www.poppi.org.uk/</a>



Haine and Smith is a regional chain of opticians with 12 branches across Wiltshire. They were pleased to help by:

- Providing the age profile of the 91,700 patients registered at their 12 Wiltshire branches, and
- Surveying activity in February 2013 at a sample of five branches to show why people present for sight tests, identify referral sources and, to see how often and to where they refer people "on" to.

#### Age Profile:

A comparison of the age profile of the patients registered with Haine and Smith to the age profile for Wiltshire (table 5 below) confirmed that people aged less than 45 are underrepresented.

Table 5: Haine & Smith - Patients By Age		% Wilts Pop'n by	Differ- ence	
Age Group	Patients	%	age	
0-17	17,416	19.00%	21.80%	-2.81%
18-25	8,964	9.78%	7.46%	2.31%
26-35	6,881	7.51%	10.92%	-3.42%
36-45	11,285	12.31%	13.48%	-1.17%
46-55	16,175	17.64%	14.99%	2.65%
56-65	12,292	13.41%	12.39%	1.02%
66-75	9,651	10.53%	10.19%	0.34%
75+	9,014	9.83%	8.76%	1.07%
Total	91,678	100%	100%	0%

#### Learning:

Assuming that the people registered at Haine and Smith are representative of people registered with other opticians across Wiltshire, this data validated the views of the Vision Ahead group members.

#### **Survey of activity at 5 branches February 2013:**

During the 4 week survey period 639 sight tests were undertaken at the 5 branches. An analysis of these at tables 6, 7 and 8 (below) gave the:

- Reasons people have a sight test,
- Source of referrals for sight tests, and
- Percentage of people "referred on" following a sight test.

	4 week sample period		Annual Estimat	
Table 6: Reason For Visit:	Number	%	Sample 5 branches	All 12 branches
Routine Eye Examination	610	95.46%	7930	40,879
GP Referral	12	1.88%	156	804
Hospital Referral	10	1.56%	130	670
Enhanced Service Referral	3	0.47%	39	201
Colorimetry Referral	4	0.63%	52	268
Total	639	100%	8307	42,822



The picture that emerges is that most (95%) of sight tests were self-referrals for a routine examination with just 5% being referrals on from other health professionals.

#### Referrals on by Opticians:

In terms of referrals "on" by opticians after a sight test:

- Table 7 below shows 6% of tests were referred on for further medical support or opinion. The majority of this was to a GP but 1.25% was to a hospital, and
- Table 8 below shows nearly 40% of referrals on (15 out of 39) are for cataracts or glaucoma.

Table 7: referrals on to where	Number in 4 weeks	% in sample	Annual Est. for Sample 5 branches	Annual Est. for all 12 branches
Hospital	8	1.25%	104	536
GP	31	4.85%	403	2,077
Total	39	6%	507	2,613
Table 8: Reasons for referrals on	Number in 4 weeks	% in sample	Annual Est. for Sample 5 branches	Annual Est. for all 12 branches
Cataracts	13	33.33%	169	871
Glaucoma	2	5.13%	26	134
Low Vision	0	0.00%	0	0
OHT	0	0.00%	0	0
Other	24	61.54%	299	1,541
Total	39	100%	494	2,546

#### **Learning:**

It is clear from the data from Haine and Smith that regular sight tests by an optician can detect potentially serious eye and other health conditions.

As we know from other sources that the earlier problems are detected the better, it is reasonable to conclude that the earlier problems are detected the better. Therefore, any measures that increase the number of people having regular eye sight tests will lead to a higher the rate of early diagnosis and lower long tern sight loss and support needs.

#### **Targeting of Sight Tests:**

The Vision Ahead members had debated the value of having sight tests annually rather than every two years in an attempt to detect eye conditions earlier in their development and had additionally debated whether more frequent sight tests should be for all or for target group? While we were in contact with Haine and Smith about their data we took the opportunity to ask their view about this?

Their view was very clearly that to be cost effective sight tests at intervals of less than two years should be for target groups only.



## Workshop 3: What we can do better and how

#### Introduction

Workshop 3 was held at the Devizes Corn Exchange on 6<sup>th</sup> February 2013 from 10.15 a.m. to 3.00 p.m. and was attended by 63 people including:

- 20 Customers or carers.
- 17 WSUN/WIN staff,
- 16 Council or NHS staff,
- 6 Representatives for third sector organisations, and
- 4 Front line care and support provider staff.

Workshop 3 experienced technical problems with the electronic voting system. This meant that there was not enough time to discuss how to prioritise the recommendations. Therefore, participants were invited to an additional (fourth) workshop held at the Devizes Corn Exchange on 14<sup>th</sup> March 2013 from 10.15 a.m. to 1.15 p.m. It was attended by 30 people including:

- 10 Customers or carers,
- 9 WSUN/WIN staff.
- 7 Council or NHS strategic staff,
- 3 Representatives for third sector organisations, and
- 1 Front line care provider representative.

#### The main aims of workshop 3 and 4 were to:

- Generate a wide range of recommendations that closed the gaps between the current care and support available and the "Ideal" defined in workshop 2
- Rationalise the wide ranging list of recommendations into a shorter specific, measurable, realistic and time bound set of recommendations agreed by the Vision Ahead Group as a whole
- Prioritise the agreed list of recommendations by allowing each member of the Vision Ahead Group to indicate their own choice of "top three" recommendations

#### The process of generating recommendations:

Workshop 3 was so well attended that we had 8 groups working on the initial generation of recommendations<sup>7</sup>. This meant:

- Three groups worked on recommendations to raise awareness of and improve understanding of sight loss,
- Three groups worked on recommendations to improve early diagnosis rates and ensure rapid access to care and support, and
- Two groups worked on recommendations to improve support to live well with sight loss.

<sup>&</sup>lt;sup>7</sup> Previous workshops had required only six groups



The initial output from the groups was 60 recommendations. Inevitably, there was some duplication between the groups so the list was rationalised to 53 recommendations during lunch. There was insufficient time in the afternoon to adequately discuss and prioritise so many recommendations.

Consequently, a fourth workshop was planned so the list of recommendations could be sharpened up and so a prioritisation process could be undertaken.

In between workshops 3 and 4 the facilitators used the feedback from workshop 3 to reduce the list of 53 recommendations down to a list of 26 for more detailed scrutiny at workshop 4.

The outcome from the deliberations at workshop 4 was 24 recommendations. Of these:

- 3 were about raising awareness and improving understanding of sight loss,
- 6 were about achieving earlier diagnosis and rapid access to care and support,
- 12 were about supporting people to live better with their long term sight loss, and
- 3 were relevant to awareness raising, early diagnosis and living well with long term sight loss

Each recommendation is presented in detail in the next four sections of the report. Each recommendation shows:

- Who Vision Ahead believes should lead on implementation,
- What specifically Vision Ahead believes needs to be done,
- When Vision Ahead believes action should be feasible,
- Why Vision Ahead believes the recommendation is needed,
- The priority given to each recommendation after the a the prioritisation exercise at workshop 4<sup>8</sup>, and
- Implementation suggestions by Vision Ahead about how each recommendation could be implemented.

#### **Priority Ratings:**

- Five out of the 24 recommendations were rated "Critically Important". These are highlighted as "Red" recommendations,
- Eleven out of the 24 recommendations were rated "Very Important". These are highlighted as "Amber" recommendations, and
- Eight out of the 24 recommendations were rated "Important". These are highlighted as "Green" recommendations

\_

<sup>&</sup>lt;sup>8</sup> Each person at the workshop was asked to identify their own personal choice of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> priority from the 26 recommendations.



## Three recommendations for raising awareness and improving understanding of sight loss

#### **Recommendation 1**

WHO	<u>WHAT</u>
Public Health	To form a cross sector working group to plan, design and run a rolling public health awareness campaign around eye conditions, how to prevent them, how to recognise possible symptoms and what to do if worried about your sight.
BY WHEN	<u>WHY</u>
Form the working group immediately. Start campaign in 12 months and continue with a rolling campaign.	Aim to develop better public awareness about eye care and how to prevent sight loss. This is important because the RNIB web site reports that:  • Almost 2/3rds of sight loss in older people is caused by refractive error or cataracts so early intervention can make a big difference as both conditions can be diagnosed by a simple eye test and prompt treatment
PRIORITY RATING	<ul> <li>Over 50% of sight loss can be avoided so prevention is crucial</li> </ul>
Critically Important	People aged under 45 are underrepresented on local optician client lists

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

The working group could include Customers, Public Health, Adult Social Care, other Wiltshire Council officers, Education (incl. pupils), the NHS/CCG and representation from the Voluntary Sector. For continuity the group should include a selection of "Vision Ahead" group members. The group should find out what is already being done and seek to co-ordinate and build on it. The campaign itself should: (1) Use a wide variety of media incl. TV, Radio, papers (2) Fund a dedicated worker to reach "hard to reach groups" and (3) Include "in reach" into youth services.



WHO	WHAT
Public Health in partnership with the Education Department.	To form a working group to plan and implement a programme of eye health care awareness raising within the discretionary element of the personal social health education (PHSE) curriculum taught in Wiltshire schools.
BY WHEN	<u>WHY</u>
Form the working group immediately. Implement the new curriculum within 12 months.	Aim to improve children's knowledge of sight loss and eye care. This is important as data from a local optician shows that young people are under-represented on local optician client lists and so are less likely to have regular sight tests. The early signs of eye disease (and other health problems) that can be detected at a sight test are therefore unlikely to be diagnosed at an early stage when treatment could be more effective.
PRIORITY RATING:	
Important	

### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

The working group could include Education (incl. pupils), Customers, Public Health, Adult Social Care, other Wiltshire Council officers, NHS/CCG and representation from the Voluntary Sector. For continuity the group should include a selection of "Vision Ahead" group members. To avoid duplication/ensure consistency this group could be a sub-group wider awareness raising group (Rec 1). To help keep costs down/quality high consider given to using retired/trainee opticians for this.



ampaign to raise awareness of the disability of sight loss and to raise public recognition of different cks.
e public awareness about and therefore sensitivity to the needs of people with disabilities incl. sight ortant because service users attending "Vision Ahead" workshop and other contributing to the "Wiltshire nsultation frequently highlighted how a better understanding of sight loss and more consideration from
ld make their day to day experience of for example travelling, shopping or working much better.
)

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

Target groups to include, but not be restricted to school children, transport staff and motorists as "Vision Ahead" members felt these groups, in particular, needed to be more aware of the needs of people with sight loss so they could be more sensitive to/considerate of their needs.

This campaign could be included in wider disability awareness campaigns.



# Six recommendations for achieving earlier diagnosis and rapid access to care and support

## **Recommendation 4**

WHO	WHAT
Wiltshire Council	To provide or commission a "One Stop Information" Team to develop and keep up to date a comprehensive set of information for people with sight loss. The "One Stop Information" Team should:
	<ul> <li>Make its information available through a network of local "One Stop Information Shops" to be established in existing locations e.g. in libraries, council community campuses/offices, hospitals, surgeries, Health Centres etc. including a mobile "one stop shop" to visit villages,</li> </ul>
	Be contactable via one telephone number, one web site and one e-mail address,
	<ul> <li>Ensure care and support providers also distribute the same information that is available in the "One Stop Shop", and</li> </ul>
	Develop an information pack about the available range of assistive technology that supports independence and regularly update it.
BY WHEN	<u>WHY</u>
Begin planning immediately. Open the first "One Stop Shops" in 12 months.	Aim to maximise independence and choice via information that is accessible for people with sight loss.  This is important because customers consistently say it is the key to enabling them be more independent e.g. the response of blind, partially sighted and visually impaired people to every consultation in Wiltshire since 2009 has emphasised how important up to date accessible information is.
PRIORITY RATING Critically Important	



#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

The information must: (1) be in a wide range of accessible formats e.g. internet, braille, large print, audio etc., (2) promote participation by people with sight loss in community activities and in shaping what is done in their communities e.g. through Local Area Boards and Community Area Partnerships (3) be tested by users (e.g. a readers panel) before it is published.

Consideration should be given to whether the existing mobile library could double up as the "Mobile One Stop Shop" recommended and an important decision will be whether the "One Stop Shop" should only be for Sight Loss or whether it could serve a wider range of needs.

Information available from other providers should be in the same range of accessible formats as in the "One Stop Information Shops"

Technology is a fast moving area and the "One Stop Shop" needs to guard against favouring one supplier. Therefore, it is important that the "One Stop Shops" research is independent, the pack is updated annually and the pack available in a full range of accessible formats.

#### **RECOMMENDATION 5**

WHO	WHAT
Acute Hospital Trusts and the CCG.	To ensure that information cards (A6 designed by the Wiltshire Council Hearing and Vision Team) that are available at Salisbury Hospital Eye Clinic are rolled out to all Acute Hospitals, clinics, GP surgeries etc.
BY WHEN	<u>WHY</u>
Immediately, as the cards already exist.	Both the Vision Ahead group members and people consulted through the Wiltshire Voices process said how important it was to be able to access information and support immediately after an initial diagnosis and how current pathways often fail to deliver this. These simple cards help to maximise independence and choice and manage anxiety by making the start of the search for information immediately after receiving an eye condition diagnosis easy.
PRIORITY RATING:	
Important	diagnosis easy.

## IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

The cards have the contact details for a selection of organisations that offer support and information appropriate for people newly diagnosed with sight loss. If a one stop information shop is created as recommended by the Vision Ahead group its contact details would need to be added.



WHO	<u>WHAT</u>
Public Health	To work in partnership with High Street Opticians/GPs to offer free sight tests to patients deemed to be "at risk" by their GP to encourage them to have sight tests at appropriate time periods
BY WHEN	WHY
Negotiate the partnership within 1 year.	The aim here is to improve screening to detect eye conditions earlier. We have already recorded how valuable prevention and early detection is (see recommendation 1), but local data shows that referrals by GP's to opticians for sight tests are relatively rare e.g. less than 2% in a sample of 639 sight tests in February 2013 were as a result of referral of a patient by a GP to an optician i.e. opportunities for early
PRIORITY RATING:	detection may be being missed.
Important	

## IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

Make the offer available to people identified as at risk by their GP and they should be given a free sight test voucher by their GP indicating their eligibility.



<u>WHO</u>	<u>WHAT</u>
Clinical Commissioning Group.	To introduce pre-school sight tests <u>and</u> re-introduce sight tests for school children at agreed ages.
BY WHEN	<u>WHY</u>
Agree new approach within 1 year.	22% of Wiltshire's 2012 population was aged 17 or less, but only 19% of customers registered with a large regional chain of opticians were aged 17 or less i.e. children are underrepresented in that particular opticians patient list i.e. some children miss out on potentially sight saving sight tests because their parents do not understand how important it is.
	A similar short fall is evident in adults aged under 45 i.e. a screening process in schools will not only increase early detection rates at school age, but it may also help to embed the habit of having regular sight tests in young adults i.e. aged 18 to 45.
PRIORITY RATING:	
Very Important	

## **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

Need to agree how often children's eyes should be tested first. This should be based on current research about the optimum ages for tests and time between tests.

To maximise coverage the tests should take place in the schools.



<u>WHO</u>	<u>WHAT</u>
All Acute Hospitals, in partnership with the Clinical Commissioning Group.	To establish Rapid Access Clinics (RAC) at each hospital with an Eye Clinic and provide improved information to Opticians and GP's about when it is appropriate to refer patients to the RAC and how to make an effective referral.
BY WHEN	<u>WHY</u>
Plan the capacity needed in the next year and open new clinics within 2 years.	To achieve a quicker specialist response after initial sight loss experience. This service is for urgent eye problems which need treatment in a few days. It can be used to circumvent the normal pathway where it is deemed to slow e.g. a GP, optometrists or accident and emergency staff can refer into this clinic by phone
PRIORITY RATING:	or fax. The service is staffed by nurses from eye casualty and a doctor.
Very Important	

## <u>IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:</u>

The RAC model referred to is already in place at Salisbury Hospital.

This model needs to be replicated at other hospitals with Eye Clinics serving Wiltshire.



WHO	<u>WHAT</u>
Clinical Commissioning Group.	To ensure a dedicated, funded Eye Clinic Liaison Officer (ECLO), with appropriate work space, to assure confidentiality, is available at all hospitals when eye clinic sessions are run.
BY WHEN	<u>WHY</u>
12/18 months to establish a business case for each eye clinic and to allow for the recruitment process.	Both the Vision Ahead group members and people consulted through the Wiltshire Voices process said how important it was to be able to access information and support immediately after an initial diagnosis and how current pathways often fail to deliver this. An ECLO would ensure emotional and practical support is available promptly after the first experience sight loss and then on an on-going basis.
PRIORITY RATING	
Critically Important	

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

There is an existing documents that the CCG could take account of it when it is establishing the business case for employing ECLO's when eye clinic sessions run at Wiltshire Hospitals:

- "Innovation and quality in sight loss and blindness services: Eye Clinic Liaison Officers" by RNIB (August 2011). It sets out the case for ECLO's quite clearly, and
- The Wiltshire Blind Association, Action for Blind People and the RNIB business case for an ECLO at Salisbury Hospital prepared for presentation to the Service Director Strategy & Commissioning at Wiltshire Council.



# Twelve recommendations for supporting people to live better with their long term sight loss

#### **Recommendation 10**

<u>WHO</u>	<u>WHAT</u>
GP's, Opticians and the "One Stop Information" shops	To all signpost people with progressive sight loss conditions, but not yet eligible for statutory services under the eligibility criteria, to appropriate voluntary and peer support groups and to statutory services in their local area.
BY WHEN	<u>WHY</u>
Begin to compile information immediately and roll out in 6 months.	Vision Ahead group members told stories about the isolating effect of sight loss and the value of emotional support from peers as well as from family, friends and professionals. Feedback recorded for Wiltshire Voices reinforced these messages.
	It was also apparent that quite a wide range of services already exist, but that people do not always know what is available how to find out what exists i.e. ensuring that the professionals most likely to support
PRIORITY RATING:	people with sight loss have comprehensive and up to date information is crucial.
Important	

## <u>IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:</u>

There should be a common set of up to date information available at all appropriate locations. The information should include a single telephone number and e-mail address where people can seek information support about all things related to sight loss.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council	To provide additional funding for peer support and buddy schemes to achieve a consistent level of access to these schemes across Wiltshire.
BY WHEN	<u>WHY</u>
12 months to identify local areas that lack capacity, set up and give funding.	To ensure emotional and practical support is available promptly after the first experience sight loss and then on an on-going basis. This is important as:
	<ul> <li>National data shows that nearly half of blind and partially sighted people feel 'moderately' or 'completely' cut off from people and things around them and that depression occurs more often. Older people with sight loss are almost three times more likely to experience depression than people with good vision, and</li> </ul>
PRIORITY RATING:	<ul> <li>Vision Ahead group members highlighted peer support groups as a strength that could be built on at workshop 1, but commented that availability varied by area and was a "post code lottery".</li> </ul>
Important	

## **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

Additional funding to be given to fund the expansion of schemes already proven to be effective into areas not currently covered and consideration should be given to how the new Community Campuses could be used as meeting place for peer groups etc.



WHO	WHAT
Adult Social Care and NHS Commissioners.	To engage with Hospitals and Nursing Care Homes to ensure they have (with the patient/residents consent) bed side signs that flag up a person's sensory impairments.
BY WHEN	<u>WHY</u>
6-12 months to set up and implement.	To help to ensure that care and support in 24/7 care and support settings is more consistently tailored for and sensitive to the individual needs of people with sight loss.
PRIORITY RATING:	
Important	

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

GWH already does this and it is a good practice that others could repeat i.e. commissioners could cite this as good practice Wiltshire Council to lobby Care Quality Commission to check compliance with this during their inspections.



WHO	<u>WHAT</u>
Wiltshire Council, Clinical Commissioning Group and Acute Hospital Trusts	To work together to ensure that all hospital "in" and "out" patient notes, GP surgery notes and notes held in people's homes all (with consent) have a flag identifying sensory impairments so that appointment letters, other communications and other support (including discharge from hospital) are delivered appropriately to each individual's needs.
BY WHEN	<u>WHY</u>
6-12 months to set up and implement.	In workshop 1 Vision Ahead group members told stories about how support they had failed to take enough (if any) account of their visual impairments e.g. GP letters in small print, Medication instructions on tiny labels on small bottles or packets and staff not taking account of their visual impairment.
PRIORITY RATING:	Having a clear flag in patient or other notes will help to ensure care and support is consistently tailored for and sensitive to the individual needs of people with sight loss.
Very Important	

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

GWH already does this and it is a good practice that others could repeat. The various forms of notes should include an individual statement about things that help the person and says how they like to be treated. Surgery Patient Participation Groups, Helped to Live at Home Service and Clinical Commissioning Group all need to help action these recommendations.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council	To form a cross sector group to develop a "Wiltshire Accessibility Standard" against which shops and other community facilities can be assessed and issue a "Charter Mark" for display by facilities that meet the standard.
BY WHEN	<u>WHY</u>
Form the group immediately, but give 2 years to set up and implement.	Vision Ahead group members explained how some everyday tasks are made unnecessarily difficult for them e.g. shopping, accessing buildings etc. This standard will help to ensure:
	<ul> <li>Community facilities can be equally accessed by blind, partially sighted and visually impaired people</li> </ul>
PRIORITY RATING:	Care and support when accessing community resources is more consistently tailored for and
Important	sensitive to the individual needs of people with sight loss.

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

The cross sector group could include Healthwatch Board, Area Boards, Customers and Chamber of Commerce.

A system for auditing the shops and community facilities to recommend how to improve accessibility and check compliance with the standard will be needed.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council	To set a new standard that "seeks to limit" the number well trained carers to a maximum of eight when people with sight loss are helped to live at home.
BY WHEN	<u>WHY</u>
Target to be agreed within 9 months, but give 2 years for	Customers within the Vision Ahead groups membership explained how important it is to have support staff who know them as individuals e.g. know what they like, dislike etc.
compliance.	Having fewer carers more often will help to ensure care and support is more consistently tailored for and sensitive to the individual needs of people with sight loss.
PRIORITY RATING:	
Very Important	

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

This standard will need to be written into contracts with care providers.

A monitoring system would allow compliance rewards and penalties to be considered.

Providers will need a reasonable time to reorganise to meet this standard.



WHO	<u>WHAT</u>
Wiltshire Council.	To calculate how many Rehabilitation Officers for Visual Impairment (ROVI) are needed to reduce waiting times for support to an acceptable level and initiate a recruitment process.
BY WHEN	<u>WHY</u>
1 to 2 years to calculate, implement, review and recruit to the new full establishment.	In workshop 1 Vision Ahead group members highlighted ROVI's as a strength as it helps people regain independence, but they also commented that the current waiting time of 12 weeks is unacceptably long and that people can become dependent and lose confidence during the waiting period. Therefore, to
PRIORITY RATING	maximise the effectiveness of "enablement" work the ROVI capacity needs to be increased.
Critically Important	

#### <u>IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:</u>

The starting point is to agree an acceptable standard waiting time, then use temporary resources to clear the backlog before calculating how many ROVI's are needed to maintain the new agreed maximum waiting time given projected workload.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council	To form a cross sector working group to explore how to best support people with Visual Impairment (VI) to retain their jobs after they experience sight loss, find new jobs and access support to sustain employment.
BY WHEN	<u>WHY</u>
Form the cross sector group immediately. Begin to implement a 4 year action plan in 1 year.	To increase employment opportunities for people with sight loss. This is important because national data shows that:
	<ul> <li>Only 1/3<sup>rd</sup> of people registered blind/partially sighted, of working age, are in work and 9 out of 10 employers rate employing blind or partially sighted people as either "difficult" or as "impossible" (DWP 2004)</li> </ul>
	Vision Ahead group members stressed the importance of support to find and sustain employment and feedback recorded for Wiltshire Voices described the devastating effect that
PRIORITY RATING:	losing employment at the same time as losing sight often has on an individual's mental
Very Important	wellbeing and financial position.

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

The group could include customers, the Hearing and Vision Team, the voluntary sector, Jobcentre Plus and Access to Work. The group should aim to raise the awareness of employers:

- · About what people with VI are capable of,
- That employing people with VI does not cost them,
- To dispel fears about Health & Safety barriers to employing people with VI,
- To generate more work placement opportunities.

The working group should also lobby Jobcentre Plus to tailor its services more for VI customer's e.g. audio job boards.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council	To work in partnership with all local bus companies to improve bus services and make them more accessible.
BY WHEN	<u>WHY</u>
Form partnership immediately and agree a long-term action plan in 1 year.	The Vision Ahead group acknowledged that bus travel has improved in recent years, but concluded that:     Further improvement was still needed to enable people with sight loss to travel more independently while remaining safe, and
PRIORITY RATING: Very Important	Relatively easy to achieve.

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

The partnership could include Customers, the Council and Voluntary Organisations. Important measures include having:

- Talking bus stops (with key fobs for those who want them) and talking buses throughout county,
- Space for assistance dogs on all buses,
- 100% accessible buses, and
- Training bus drivers not to move on until everyone is seated.



<u>WHO</u>	<u>WHAT</u>
Wiltshire and Swindon Users Network	To lobby licencing authorities, on behalf of the Vision Ahead Working Group, to require that taxi and bus companies to include regular (e.g. annual) equality training, which includes Visual Awareness, for all staff as part of their licensing arrangements and to develop arrangements to check that the training is effective.
BY WHEN	<u>WHY</u>
Initiate consultation immediately. Aim to implement within 1 year.	To enable people with sight loss to travel more independently while remaining safe.
PRIORITY RATING:	
Very Important	

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

To test effectiveness the licencing authorities (i.e. VOSA Traffic Commissioner for vehicles with 9 or more seats and Wiltshire Council for private hire and taxi vehicles with less than 9 seats) should develop a monitoring system that includes:

- Mystery shopper, and
- The analysis of complaints.



WHO	<u>WHAT</u>
Wiltshire Council working through Local Area Boards and with enforcement staff e.g. parking and licencing authorities.	To enforce rules about vehicles parking on pavements and about pavements being blocked by street furniture and other obstructions e.g. advertising boards, wheelie bins etc.
BY WHEN	<u>WHY</u>
Each Local Area Board to invite parking enforcement teams and the local police to their next meeting.	At workshops 1 and 2 of Vision Ahead customers told stories about how thoughtless parking and random other obstacles on pavements can be difficult for people with sight loss to negotiate their way around and can be dangerous on occasion. This was also a theme of Wiltshire Voices.
PRIORITY RATING: Very Important	Using a combination of enforcement and education to minimise such obstacles will enable people with sight loss to travel more independently while remaining safe. Local Area Boards were seen as a good local body to gather information from local people about places with the most serious issues so that action could be prioritised.

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

Local Area Boards (using a local champion and after consulting local people and voluntary organisations to identify local trouble spots) to lobby local parking and other enforcement teams and ask them for evidence that enforcement has been effective.

Where enforcement is not the best answer Local Area Boards should consider local education and publicity campaigns.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council.	То:
	<ul> <li>Promote the new system for reporting problems with pavements (planned to replace the current Clarence system) in a targeted way to blind, partially sighted and visually impaired people, and</li> </ul>
	<ul> <li>Ask Local Area Boards to establish a local system to monitor the state of pavements (including overhanging braches) in their area and report repair requirements to the recently appointed Council Highways Department Community Co-ordinator.</li> </ul>
BY WHEN	<u>WHY</u>
6 months to establish the new system.	At workshops 1 and 2 of Vision Ahead customers told stories about how uneven pavements can be difficult for people with sight loss to negotiate, undermine their confidence and be dangerous tripping hazards. This was also a theme of Wiltshire Voices.
PRIORITY RATING:	Local Area Boards were seen as a good local body to gather information from local people about places with the most serious issues so that action could be prioritised.
Important	Better maintained pavements would help to enable people with sight loss to travel more independently while remaining safe.

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

Each local Area Board to invite feedback from the local population about pavements that need repair and then invite the Council Highways Department Community Co-ordinator to their next meeting to agree how information collected about their local area can best be collected, collated and reported e.g. into the new system that is replacing the existing "Clarence" system.



# Three recommendations relevant to awareness raising, early diagnosis and living well with long term sight loss

#### **Recommendation 22**

WHO	<u>WHAT</u>
Human resources and contracts sections within Wiltshire Council and the Clinical Commissioning Group.	To ensure contracts and service level agreements require:  • Eye health care training to feature in induction training for all front line care and support staff, and  • All nurses and care home staff to have sensory loss training that is updated regularly.
BY WHEN	<u>WHY</u>
A rolling implementation programme as contracts are let or re-let.	Vision Ahead group members saw this basic training requirement as being a fundamental first step in the "up skilling" of care and support staff so they can support people with sight loss more effectively.
PRIORITY RATING:	
Very Important	

#### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

Make this a contractual requirement for any care or support provider contracted to Wiltshire Council or NHS and ensure service level agreements with in-house providers have the same requirements.



<u>WHO</u>	<u>WHAT</u>
Wiltshire Council and the Clinical Commissioning Group.	To allocate responsibility for the implementation and on-going development of a "Joint" Vision Impairment Policy/Strategy to named, and therefore accountable, senior staff.
BY WHEN	<u>WHY</u>
Initiate joint planning immediately, finalise the policy/strategy in 1 year.	To ensure policy development and strategic planning are properly informed and influenced by a clear and consistent strategic direction.
PRIORITY RATING: Very Important	This also helps customer and patient groups hold management accountable if the strategy is not delivered or if decision are taken that do not seem in line with the agreed strategic direction.

#### **IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:**

The policy and strategy should be supported by data/evidence based incl. Joint Strategic Needs Analysis and take account of the Vision Ahead Working Group's recommendations and the findings from the Wiltshire Voices Project.

Once agreed the strategy should be acted on, and named senior staff should be held accountable for delivering the strategy.



#### **RECOMMENDATION 24**

<u>WHO</u>	WHAT
Clinical Commissioning Group (CCG)	<ul> <li>To:         <ul> <li>Appoint an associate eye specialist to champion Visual Impairment (VI) and to link with Healthwatch, and</li> <li>Ensure each area CCG has an associate ophthalmologist on it.</li> </ul> </li> </ul>
BY WHEN	<u>WHY</u>
From April 2013 onwards.	To ensure policy development and strategic planning are properly informed and influenced by experts in
PRIORITY RATING: Very Important	sight loss.

### IMPLEMENTATION SUGGESTIONS FROM THE VISION AHEAD GROUP:

To ensure this is implemented the support of Directors and Chief Executive Officers may need to be sought to ensure they nominate an Ophthalmologist or other suitable person for each area CCG.



## **List of Annexes:**

Annex 1	Participants hopes and fears identified at workshop 1
Annex 2	Features of good support identified at workshop 1
Annex 3	Strengths and improvement opportunities identified at workshop 1
Annex 4	Care and Support in the Ideal World identified at workshop 2
Annex 5	Gaps compared to the ideal world identified at workshop 2
Annex 6	Recommendations in font size 16 and printed black on yellow from Workshops 3 and 4