

CHESHIRE SIGHT LOSS INFORMATION SURVEY

SUMMARY REPORT

1. Purpose of the study

The purpose of the study was to find out how people in Cheshire accessed information to support their vision impairment and what information was most useful to them. The overall aim of the project is to improve information for people with sight loss in Cheshire and is a partnership between NHS England, Vision Support and East Cheshire Eye Society.

2. Methodology

The population chosen for the research was people with sight loss in Cheshire. The total number of people registered as vision impaired in Cheshire East, Cheshire West and Chester and Halton is 6,515. (RNIB 2022). Please note there are issues with the accuracy of registration data. The RNIB estimates this figure to be much higher at 32,990.

Number of surveys distributed. Non random sampling was used with over 1,600 (check) surveys sent out to VI people on mailing lists (convenience sampling) and snowball sampling where surveys were available online and sent to resource centres, eye clinics and local authority rehabilitation teams for distribution.

The questionnaire was a mixed methods survey with quantitative (closed) and qualitative (open) questions to allow more in-depth answers from respondents. The data was analysed using descriptive statistics which help describe or summarize data in a meaningful way. There were 146 returns. 92% were paper returns and 8% were online.

3. Findings

3.1 Demographics

Gender – The highest percentage of respondents were female 61%, 38% were males, 1% were transgender and 8% preferred not to say.

Age – The highest percentage of respondents were 65 or over - 78%, 10% were 55 – 64, 10% were 25 – 54 and 2% were under 25. 8% preferred not to say.

Ethnic Background – The highest percentage of respondents were White – 95%, 2% were Black/African/Caribbean/Black British, 2% were Asian/Asian British and 1% were Mixed. 11% preferred not to say.

Post Town – The highest percentage of respondents were from Chester – 18%, 14% were from Macclesfield, 13% were from Runcorn and Northwich, 12% were from Widnes, 5% were from Wilmslow and Alderley Edge, 4% were from Stockport and Knutsford, 2% were from Ellesmere Port, Neston, Frodsham, Congleton and Nantwich, 1% were from Crewe, Winsford, Sandbach, Stockport, High Peak, Malpas, Warrington. 8% of total respondents preferred not to say.

Please note when one than more post town is mentioned the % relates to each post town.

Sight Loss Registration – The highest percentage of respondents had a CVI Severely Sight Impaired – 41%, 33% had a CVI Sight Impaired, 15% had sight loss but no CVI, 9% had no registration status and 2% preferred not to say. 29% of total respondents did not answer the question.

Please note staff who assisted people completing the survey reported many did not understand sight loss registration status or the process and some respondents wrote additional comments explaining this on the forms.

Years With A Vision Impairment (VI) – The highest percentage of respondents had a VI for between 1 and 10 years – 48%, 17% had a VI between 11 – 20 years, 13% between 21 to 30 years, from birth – 8%, between 31 to 40 years – 6%, 41 to 50 years – 3%, 51 to 60 years was 3%, over 60 years was 2%. 17% preferred not to say.

3.2 Response to Questions

Q1 How have you accessed information in Cheshire for people with sight loss

The highest percentage of people accessed information 56% from NHS Hospital Ophthalmology, 42% from the Low Vision Service, 39% from local charities, 32% from friends and family, 24% from national charities, 23% from Cheshire Council's Rehabilitation Service, 22% from the NHS Eye Clinic Liaison Officer and 11% from Other. 3% of total respondents did not answer.

For the 'Other' question 10% said Vision Support, 8% said East Cheshire Eye Society, 6% said the Macular Society, 4% mentioned Blind Veterans, Halton Borough Council, NHS, RNIB and 2% said the National Eye Society, Alex, Family and Friends, Blind Association, British Telecom, Cheshire East Local Authority, Age UK, Iris, Low Vision Service, Dial A Ride, VIVA Assist, Macclesfield General, Specsavers Runcorn, Internet, Weaver Vale Housing Trust, Northwich Library and a local optician.

Please note when more than one organisation is mentioned the % relates to each organisation.

Positive comments were made about specific individuals in Widnes Social Services x 3, Macular Society and Vision Support.

Negative comments were made about getting no information or a lack of information x 2, the local authority x 2, Low Vision Service meetings stopping x 1, reduction in Dial A Ride services x 1 and hospital information x 1.

Q2 How Satisfied Were You With The Following?

People had the highest levels of satisfaction with the information received being helpful (77%) and being given the right information at the right time (70%). Lower levels of satisfaction related to not being able to contact someone easily to get information (57%), not knowing who to contact for more information and support (67%) and not being given information in their preferred format (67%).

Further comments were provided by 37 respondents. Positive comments related to:-

- sight loss charities x 9
- information from NHS/ECLO x 7
- local authority services and national charities x 2
- signposting from charity and friends and family x 1

Negative comments related to:-

- did not know any information/limited information/lack of support/would like more information x 15
- information not in an accessible format x 10
- quality of services varies x 2

Q3 What Kind Of Information Did You Find Most Useful To You?

Most people found information about low vision aids and equipment (68%), information about their eye condition (56%), benefits advice (45%), social groups and activities (42%) and signposting to organisations (32%) most useful to them. Less useful was information about travel and transport (29%), health and well-being (24%), education and training (23%), digital skills (26%), rehabilitation (17%) and employment (2%).

Q3a If You Received Information About The Following, How Did You Receive The Information?

Over 40% of people did not receive information about or did not answer the question relating to employment, rehabilitation, education and training, travel and transport, emotional support/counselling and health and well-being.

43% reported receiving printed information from the hospital about their eye condition, with 49% getting information about their eye condition from other sources. Apart from employment, rehabilitation and signposting to other organisations, the highest percentage of people reported getting information about emotional support, health and well-being, education and training, social groups and activities, benefits advice, travel and transport, low vision aids and equipment and digital skills from charities and groups.

Q4 What Three Services Did You Find The Most Useful?

97 people answered this question or 66%. This was an open question.

- 32 % Aids and equipment
- 26% Low vision services
- 20% Social Groups and Activities
- 18% Benefits Advice
- 14% Someone to talk to about sight loss/eye condition
- 14% Vision Support
- 11% Digital Skills and Family and Friends
- 10% NHS Ophthalmologist

- 9% East Cheshire Eye Society
- 8% Rehabilitation and Macular Society
- 7% RNIB and Travel and Transport
- 5% Counselling and Emotional Support
- 4% Local Authority
- 3% Guide Dogs, Signposting to Social Care, Blind Veterans, Local Charities

Mentioned by one or two people were GP services, opticians, library services and other national and local charities.

Q5 How Do You Prefer To Get Information? More Than One Option Could Be Chosen

142 people answered this question.

Face to face was the preferred option – 73%

Over the telephone – 49%

Newsletters – 46%

By email – 25%

Finding it online – 11%

Social media – 3%

Q6 This Is Your Opportunity To Tell Us About Any Barriers To Finding Out Information About Sight Loss And Support In Cheshire And To Provide Further Comments

78 people answered this question. This was an open question.

Positive Themes

28% said they had help from local charities

12% said they do not need help, no barriers identified, were independent

10% said they had help from their local council

4% had help from family and friends and the internet

3% had help from opticians

1% had help from NHS, Low Vision Services and national charities

Negative Themes

32% said they had not had information, there was a lack of information and/or they did not know where to get information.

9% said information was not in accessible formats

9% said COVID had reduced services and stopped face to face activities

4% said there was no joined up or coordinated approach to providing information

3% said there was an overreliance on the internet and computers and it depended on the attitude of person giving the information

1% said information was not up to date, there was a lack of face to face contact, lack of confidence is a factor, there should be more information about eye health and eye checks and packaging is very inaccessible.

Q13 Tell Us About Any Other Long Term Health Condition You Have, Which Affects Your Quality Of Life

96 people answered this question. This was an open question.

66% of respondents had other long term health conditions and some had more than one health condition including:-

36% - mobility and orthopaedic issues

20% - arthritis/osteoarthritis

15% - deafness/hard of hearing, diabetes Types 1 and 2

5% - stroke, COPD

3% - Alzheimer's/dementia, asthma, hernia, mental health, depression, anxiety, eating disorder

2% - cancer, high cholesterol, fibromyalgia, IBS, Parkinson's, Multiple Sclerosis

1% - amputee, carpal tunnel, chronic fatigue, eczema, epilepsy, high blood pressure, immune systems issues, tinnitus, water on the brain.

76 people entered the Prize Draw.

4. Limitations Of Study

The lack of accurate and reliable sight loss statistics makes it difficult to estimate a sample size which is representative of the population. Therefore, there is no objective way of evaluating the reliability of sample results. Snowball sampling is also reliant on other organisations distributing the survey and could introduce bias if one organisation promoted the survey more than others.

Completing surveys can be challenging for people with sight loss and can be difficult to navigate, particularly on paper. Only 8% of surveys were completed online where questions cannot be missed out. 92% were paper survey returns with answers to questions missing. There were a number of open questions which do not allow for the analysis of results using numerical measures and are based on approximates and themes.

5. Conclusion

To be discussed at the Steering Group and by the Project Team.

Factors to consider:-

1. Can the presentation of the data be improved?
2. Are the demographics reflective of Cheshire?
3. Do the results support other research relating to accessing information?
4. How accurate are the results? Do they seem biased or a true reflection of people's views and experiences?
5. What can be concluded from the results?
6. What recommendations would you make?