



**Eye Health Needs Assessment
Patient and Public Engagement**

1. Introduction

What is Healthwatch?

Local Healthwatches have been set up across England to create a strong, independent consumer champion whose aim is to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs and
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting.

Healthwatch Stockton-on-Tees works with local people, patients, service users, carers, community groups, organisations, service providers and commissioners to get the best out of local health and social care services. This doesn't just mean improving services today but influencing and shaping services to meet the needs of the local communities tomorrow.

What is an Eye Health Needs Assessment?

The North East and Cumbria Local Eye Health Network has incorporated an Eye Health Needs Assessment into its work priorities for 2013/14- 14/15 for the Durham, Darlington and Tees area. The EHNA seeks to provide a sound strategic evidence base to inform the future commissioning of locally determined eye services based on need, available evidence and current service mapping. It will encompass an equity audit to evaluate service provision alignment to need and assess delivery of national standards. It is intended to contribute to long term goals of a reduction in health inequalities; improved service provision and access and a reduction in service quality variation across the patch.

Feedback from patients and the public is a vital part of this to ensure a full picture of service need, access, quality and value is obtained. It will ensure that any future eye care commissioning decisions are informed by patient and public insight.

Healthwatch has completed the patient and public engagement for the Eye Health Needs Assessment in Stockton-on-Tees. This has allowed us to provide an independent perspective on local Eye Health Needs ensuring that a voice is given to seldom-heard communities and 'At Risk' groups.

2. Methodology

Healthwatch Stockton-on-Tees collected patient and public feedback to meet the below requirements:

1. Analysis and collation of eye care related intelligence previously gathered through Healthwatch engagement mechanisms including the Information and Signposting service, targeted engagement with seldom heard groups and grass roots information supplied by Partner Organisations, Healthwatch Members and Information Volunteers.
2. A survey completed by Service Users and Carers which asks for specific information on their experience of accessing and using particular eye health services.
3. Engagement with non-service users who are at risk of developing eye health problems or who are from vulnerable/ traditionally seldom heard communities. Engagement delivered in a Focus Group format to enable exploration of people's awareness and understanding of the prevention agenda for eye health.

Service User and Carers Survey

The survey used was designed to illicit responses from Service Users about their experiences of both accessing and using eye health services. Service Users were also prompted to comment on where there may be gaps in provision or pathways to access services as well as highlighting their awareness of lifestyle factors which may prevent eye conditions.

A range of approaches have been used to collect feedback from users:

- Face to face survey work in a range of healthcare settings such as James Cook University Hospital Ophthalmology Department.
- Survey Monkey cascaded and promoted throughout the Healthwatch Stockton-on-Tees network of over 100 organisations and 50 individual members.
- Service Users targeted for engagement through eye clinic liaison workers and specific organisations who work with people with sensory impairments, eg. Teesside and District Society for the Blind, Action for Blind People.

In total, 41 Service users and carers completed the questionnaire through the above methods of engagement.

Focus Groups with Non-Service Users

Focus Group 1- Asylum seekers and people from the BAME community

It was determined that a focus group take place with asylum seekers and people from the BAME community. This decision reflects demographic information that the BAME population of Stockton-on-Tees is higher than the regional average. Recent intelligence from the North East Refugee Service also indicates that Stockton-on-Tees and Middlesbrough have a higher number of Asylum Seekers residing in the locality than in other areas of the North East. This population demographic, coupled with Public Health information highlighting the BAME community as being a group at risk of developing eye conditions suggests that engagement with this group will be useful in exploring awareness and attitudes to eye health prevention messages.

Focus Group 2- the Deaf Community

It was considered important to undertake a Focus Group with a group with a particular health condition. Deaf people have been identified as a group at risk of developing eye conditions and also have specific needs when accessing appointments and services. It was therefore felt that detailed engagement with this group would provide a useful insight into their experiences.

3. Responses

Service user and carer survey

Total Number of Responses	41		
Service Users	35		85.37%
Carers	6		14.63%
Registered as:	Sight impaired (partially sighted)	8	21.95%
	Severely sight impaired (blind)	22	19.51%
	Sight problems but not registered	2	53.66%
	Don't know	2	4.88%
How long diagnosed with a sight condition?	From Birth	1	2.5%
	Under 1 year	3	7.5%
	1-5 years	16	40%
	More than 5 years	8	20%
	More than 15 years	12	30%
Ethnicity	White	35	85.37%
	White other	1	2.44%
	White and Black Caribbean	2	4.88%
	Asian	2	4.88%
	Black African	1	2.44%
Age	Under 18	2	5%
	18-29	2	5%
	30-39	2	5%
	40-49	2	5%
	50-59	2	5%
	60-69	6	15%
	70-79	7	17.5%
	80-89	17	42.5%
Gender	Male	10	24.39%
	Female	31	75.61%
Local Authority Area	Stockton-on-Tees	41	100%
Services used for eye health	Local optician	33	80.49%
	Local GP	11	26.83%
	Hospital Ophthalmology Departments	24	58.54%
	Eye Clinic Liaison Officers	2	4.88%
	Pharmacist	3	7.32%
	Eye Casualty/ A&E for Urgent Eye conditions	1	2.44%
	Voluntary/ community organisations	13	31.71%

	Local council/social care/ rehabilitation/ sensory support services	3	7.32%
Time taken after noticing symptoms to getting advice	Within the same day	5	12.82%
	Within a few days	10	25.64%
	Within one month	8	20.51%
	Within 6 months	12	30.77%
	6-12 months	0	0
	12 months	2	5.13%
	Longer than this	2	5.13%
Where did you first seek advice?	GP	14	38.89%
	Optician	23	63.89%
	Pharmacy	0	0
	Practice Nurse/ nurse	0	0
	A&E	0	0
	Urgent care/ walk in	0	0
	Eye casualty	1	2.78%
	Dialled 999	1	2.78%
	Dialled 111	0	0
	I looked on the internet	0	0
Did you look anywhere else for information first?	Searched on NHS Websites	2	20%
	Searched non- NHS websites	0	
	Used a Phone App	0	
	Asked friends and relatives	7	70%
	Carer/ social worker	2	20%
	Voluntary/community/faith group	0	0
	Local Healthwatch	0	0
Did anything stop you from seeking advice sooner?	I didn't delay in seeking advice	29	82.86%
	I didn't know where to get advice	2	5.71%
	I was scared or anxious	3	8.57%
	I didn't think it was important	2	5.71%
How well supported did you feel after you were given your initial diagnosis.	Very well supported	17	42.50%
	Fairly well supported	15	37.50%
	Minimally supported	3	7.50%
	Not supported at all	5	12.50%
Services you have accessed since your diagnosis	Optician	30	75%
	Local GP	11	27.50%

	Hospital Ophthalmology Department	30	75%
	Eye Clinic Liaison Officer	1	2.5%
	Pharmacist	2	5%
	Eye casualty/ A&E	1	2.5%
	Voluntary/ community organisations	12	30%
	Local council/ social care/ rehabilitation/ sensory support services	4	10%
Awareness of the link between listed factors and increased risk of sight problems	High Blood Pressure	18	45%
	Diabetes	27	65.85%
	Unhealthy diet	15	37.50%
	Lack of exercise	8	20.51%
	Smoking	13	32.5%
	Alcohol/ drug misuse	10	25%
Before diagnosis, how often did you have your eyes tested?	Annually	15	37.5%
	Every 2 years	16	40%
	3-5 years	2	5%
	Only had them tested once or twice in my lifetime	3	7.5%
	Never had them tested	4	10%
How easy do you find accessing eye tests?	Very easy	19	51.35%
	Fairly easy	15	40.54%
	Quite difficult	3	8.11%
	Very difficult	0	0
What would encourage you to have more eye tests?	More information about the risks and benefits	14	82.35%
	Closer opticians	0	0
	Cheaper eye tests	4	23.53%
Service with the biggest impact	Optician	20	48.78%
	GP	7	17.07%
	Hospital Ophthalmology department	21	51.22%
	Eye Clinic Liaison Officer	1	2.44%
	Pharmacist	1	2.44%
	Eye Casualty/ A&E	1	2.44%
	Voluntary/ Community groups	10	24.39%

	Local council/ social care/ rehabilitation/ sensory support services	2	4.88%
How well do services work together?	Very well	8	25.81%
	Fairly well	10	32.26%
	Minimally well	6	19.35%
	Not well	7	22.58%
How well informed do you feel about your eye health care?	Very well informed	17	41.46%
	Fairly well informed	12	29.27%
	Minimally well informed	5	12.20%
	Poorly informed	7	17.07%

Do you have any particular health, social care, information, support needs that are not met by current services

General awareness by the general population of sight conditions to support people.
 When road works should consider installing aids for crossing the road.
 The social worker who visited after registration was not very helpful. When I asked about financial assistance she thought it was not applicable although I have friends who were/are awarded assistance.
 I would use other services if I knew about them. I would like more information on risks to eye health and how I can keep my eyes healthy.
 Easier access, improved information at appointments, closer liaison between the clinic and transport providers. Being diabetic and having dementia my mother gets confused and is vulnerable as she has to eat regular meals.
 Information / appointments not sent to me in my preferred format.
 I struggle with cleaning and transport

What more information, support, advice, input would have helped at the different stages of your experience?

Support to attend appointments and to get around in the hospital.
 Help with getting around. Mobility training. Access to information.
 Psychological effects.
 Would liked to have known more about macular degeneration. No one really explained until too late.
 One phone number. Local hospitals used.
 A single point of contact for any concerns.
 Even finding your way through the hospital is difficult. A porter can be requested to help infirm people but they often walk so quickly it is hard keeping up with them!!

The clinic at James Cook is far too busy I feel ill when I come home having to stand for such long periods at a time. Getting there is a nightmare having somewhere closer to home would be a big help. There are lots of suitable hospitals and clinics around which are not being used???

Everything was fine

Focus Group 1 Asylum seekers and people from the BAME Community

Focus Group	<p>North of England Refugee Service The Life Store Middlesbrough 29th April 2014 10 people</p>
Attendees	<p>A wide representation of community leaders from several groups were present including the Romanian Assembly, North of England Refugee Service, Tees Valley Mano River Union, Straight Forward, Investing in People and Culture, West Africa (Guinea, Sierra Leone and Liberia) and The Other Perspective.</p>
Discussion	<p>What eye health services people were aware of? Collectively the group had heard of opticians, doctors, hospitals and laser surgery.</p> <p>What eye services have you used here locally? GP for eye infections, opticians.</p> <p>What stops you accessing eye health services? The price of eye tests, cost of glasses, language barrier. It is our culture to avoid glasses until the very last minute. It is our culture to avoid glasses until we cannot do without them. We would not go to the doctor or optician until we were almost blind. Eye health is not something we would think about in our culture. Parents do not understand the importance of eye health and so do not pass it on to their children. Lack of information- don't know what services allowed to use or entitled to (e.g. one lady thought you had to register with an optician and get a referral from GP for eye test). Romanian culture- pride in self appearance- glasses frames may not always be suitable- bullying was also mentioned.</p> <p>What would make you use eye health services more?</p>

Education-I was unaware that going for eye tests could screen for other health issues.

I was unaware that things such as life style, lack of exercise, drinking and smoking may affect my eyes.

Having a budget optician in my town, the one in my town is too expensive.

Free eye health screening to look for things such as brain tumours, diabetes held in our local community groups.

Interpreters or leaflets in one of the 5 main languages spoken. Use community proofing on any materials or leaflets to ensure information is in most suitable format.

More information and emphasis on risks to health and what could happen if you don't get regular check-ups. When asylum seekers first arrive, the emphasis is on physical health and information on other ways to look after yourself e.g. eyes can be obtained from receptionist staff. People who are destitute may not have a phone to make an appointment for an eye test or be able to get along to one. Would it be possible to provide free screening on initial arrival to area for people who are destitute?

How would you like to find out the information?

Health professionals coming to talk to our community groups (Community leaders in particular) and also tap into existing organisations such as NERS to provide briefings about risks and benefits and to tell us what to look out for, where to go and what help we can get. That way we would have someone on hand to translate and it would bridge the gap for communities who are less able and confident to seek help.

Education in schools for the children involving the parents.

Currently if a child comes home with a leaflet we would not take any notice as we have not used such services so would not realise the importance. We do not know what is available, what is charged for etc.

You could train some of our community to pass on the information face to face, culturally we respond much better to verbal communication than written. Ideally this would be in support centres we already use. The staff here try to educate us the best that they can but they are often unaware of things such as eye health themselves.

Verbal information works best but you need to build up trust of the communities perhaps by involving community.

Information available in community centre and voluntary centres.

Use Refugee Week (14th June) to share information as communities will be readily available to engage with and educate.

	Mobile community bus.
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Focus Group 2- Deaf Community

Group	The Access Gateway Catalyst Building, Stockton 15 th May 2014
Attendees	7 deaf and hard of hearing people. There were a range of different hearing needs including people who could lip read and those who required a BSL interpreter to support them to give their opinions.
Discussion	<ul style="list-style-type: none"> • The group identified a range of services for eye health including the optician, GP, ophthalmology department at the hospital and charities for sensory impairment. • The group were aware that having diabetes gave people a higher risk of developing eye conditions. One person already knew that there was a link with having high blood pressure. However, they were unaware that there were links to other lifestyle factors such as lack of exercise. • None of the group were aware that being deaf put them at a higher risk of developing an eye condition. There was some discussion around whose responsibility it is to give out that information and the group felt that the GP should outline this during check-ups as people would be unlikely to take on board information from public health campaigns. The group were surprised that their likelihood of developing an eye condition was increased due to their hearing impairments. They expressed that they value their sight more than hearing people and are keen to protect it. • People stated that they attend eye tests when sent for by letter by the optician. This varied within the group but was either annually or every two years. • The group talked about experiences of having an eye test and it was generally felt that the process is challenging for a deaf patient to follow. People were frustrated that they

often had to use the telephone to make an appointment. It has to be a hearing family member who makes the phone call and people felt that this was discriminatory- they would rather have control and flexibility over making their own appointments. People commented that the barriers linked with making an appointment would deter them from having more frequent eye tests.

- When a deaf person goes to the optician, if there is no BSL translator with them, it can be a traumatic experience. The optician is not able to tell them what is going to happen and what to expect- often they rely on pointing to tell the deaf person what to do. People commented that this makes them anxious and reluctant to go for regular check-ups.
- There were big concerns regarding interpreters. People were very unclear about whose responsibility it is to fund an interpreter to attend an eye test with a deaf person. The group felt that this cost should not be theirs to meet. However, they did not want to take the chance of being responsible for picking up this cost and therefore did not pursue the issue even though having an interpreter with them would be beneficial. There is some confusion around whether, as private companies, opticians such as Spec Savers could refuse to fund an interpreter. People felt much less likely to ask for an interpreter for an optician's appointment than they would at a GP appointment.
- Some deaf people's first language is BSL. This presents additional barriers when accessing services. It was felt there is a general ignorance of the needs of deaf people within the Health Service- someone commented that professionals treat you as a second class citizen if you cannot hear what they are saying. It is disempowering not to have all the information about your own medical condition and having to rely on family members and neighbours to help you out with personal issues. One group member commented that professionals often wanted to use her young son to translate. This, she felt was very inappropriate as he should not be put in a position where he has to give his mother potentially bad news about her eye health.
- People felt that glasses are too expensive and they should get additional support from the NHS to pay for their prescriptions. Some people struggle with inadequate glasses as they can't afford new ones.

	<ul style="list-style-type: none"> • There was much discussion around how they could encourage their peers to have eye tests more frequently. It is very important that face to face communication occurs with deaf people in order to get the message across. A community development approach to profile raising is preferable to public awareness campaigns. Although many deaf people do use the internet and Facebook in particular, not everyone does and it is therefore important to have a range of approaches. • There was agreement that messages should come from the GP. This would ensure that people took it seriously. Someone suggested that there should be a trigger within medical records which prompts the GP to remind the patient about being at risk of eye health conditions. • Opticians in particular need to have comprehensive training about the best way to support deaf people to access their services.
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4. Key Findings

Service User and Carer Survey

Preventing eye care problems

There was a poor awareness among respondents of the factors which can increase risk of developing eye conditions.

People had some awareness of the link between health conditions- diabetes and high blood pressure- and an increased risk of eye health deterioration. However, fewer people were aware of a link to lifestyle factors such as drinking alcohol and a lack of exercise. Over 65% of people were aware of the link to diabetes compared to 20% of people knowing about a link to a lack of exercise. This lack of awareness suggests that people will be less likely to prevent eye health conditions by living healthier lifestyles.

Over 80% of respondents stated that having more information on the risks and benefits linked to eye health conditions would encourage them to have more eye tests. This suggests that people would like to be better informed about preventing eye care problems and therefore providing information in an effective way could encourage people to take better care of their eyesight.

However, contrary to this, most people said that they felt either very well informed or fairly well informed about their eye health. This could indicate that people do not identify preventative messages as being aimed at them as individuals.

The majority of respondents took up to one month to access advice when noticing symptoms. Similarly, over 80% of people did not feel that they had delayed in seeking advice. Very few people commented that anything had stopped them from seeking advice. This could suggest that people do access services once eye health problems begin to surface.

Sight test access and provision

Nearly 80% of those who took part in the survey stated that they had eye tests either annually or every 2 years. Over 90% stated that they found eye tests very easy or fairly easy to access. This suggests that people feel that they currently look after their eye health and do not need to undertake further measures to prevent deterioration.

82% of respondents commented that if they were given more information about risks and benefits of frequent eye tests, they would be more likely to follow this advice by having eyes tested on a more regular basis.

23% of people said that cheaper eye tests would have encouraged them to have more frequent checks. This low response might be explained by again examining the age profile as detailed above.

No-one commented that having closer opticians would encourage them to attend more regularly. This is interesting when the age profile of respondents is considered. Nearly 60% of people were over the age of 70 and which would imply that they would be more likely to have mobility problems and therefore location of service would be more important to them. It suggests that the location of opticians in Stockton-on-Tees is adequate for those questioned.

Expense of eye tests and glasses is an issue within the BAME community. This is particularly true for Asylum Seekers who face big barriers in terms of finance already. It is difficult for them to prioritise eye health when they are sometimes struggling to feed and clothe their children. This suggests that it might be beneficial to explore ways in which these vulnerable groups can be offered support.

Assessment, diagnosis and treatment

By far the services utilised most frequently were Opticians, GPs and Ophthalmology Departments within the hospital with over 80% of people using the optician.

There seems to be a lack of utilisation or awareness of other services. For example, only 2.44% of people said they used eye casualty and less than 5% of people mentioned an Eye Clinic Liaison Officer. This could suggest that people are unaware of other services or that those services are not meeting their needs. Someone commented that they would use more services if they were aware of them.

The majority of people said that they had looked for information from family and friends before accessing a service when they first noticed symptoms. Notably, no-one said they had used a non- NHS website or a phone app. This could indicate that these services are not relevant or known to the people who undertook the survey.

The services people felt had the biggest impact were the Hospital Ophthalmology Department and Optician. This could be because these services deliver the majority of treatment and diagnosis of conditions. Interestingly nearly 25% of people stated that a voluntary or community group had the biggest impact on their condition. This indicates that people value community based support.

People wanted a single point of contact for all issues related to their sight.

James Cook Hospital is very busy and people who are blind and partially sighted find it difficult to access. Often there are no seats left in the waiting room and this creates problems for those with mobility issues. This was also commented on by staff who found it a very busy and chaotic environment. Community based provision was suggested.

The focus group in the BAME community identified that there are a number of cultural barriers preventing people from accessing services. This seems to be particularly around people ignoring symptoms and being unaware of risks to eye health. Many parents do not have their children's eyes tested. People are keen to become more educated about eye health

Rehabilitation, advice and support

A large proportion of people highlighted voluntary/ community services as being the most important service for them. This suggests that people have a positive experience being supported by these services- many people indicating that they value this service more highly than clinical services.

There was a general lack of awareness of the service provided by ECLLO. A note from the staff supporting completion of the survey highlighted that ECLLO services

needed to be explained to many people as they were not even aware of it. Where someone had accessed an ECLO, they indicated that the service had biggest impact on their treatment. This suggests that there may be a need for further ECLOs in Stockton-on-Tees.

Information and Communications

A suggestion was made that the general public needs to be more aware and supportive of blind and partially sighted people within the community. If more people were informed, then people could be more independent. It was suggested that there should be some awareness training and a public campaign as well as teaching it in schools.

Information and communications are clearly very important issues within the BAME and deaf communities.

People felt that information needs to be accessible in a variety of languages and that an interpreter should be available to support them at appointments.

Within the BAME community, people are keen to become more educated about eye health, what services are available and how they can prevent sight loss. This needs to be in accessible formats for example, different languages or through the use of community champions. People also felt it is vital to educate children within their community in order that prevention can take place.

People in the deaf community were not aware that they are in a group at risk of developing eye health problems. They felt that this should be emphasised when being invited to eye tests.

Making and attending appointments is an area which could be improved. Deaf people do not like to have to ask friends and relatives to make appointments on their behalf or to translate through BSL for them. People want an interpreter to support them during eye tests. Issues of cost need to be clarified to both the deaf community and to opticians.

5. Thanks

Healthwatch Stockton-on-Tees would like to thank all those people who participated in our focus groups as well as those who completed the Service User and Carer survey. Many thanks also to our Healthwatch members who have supported us to access people who use eye health surveys and are in at risk groups.

For more information on Healthwatch, please visit our website www.healthwatchstocktn.co.uk