Written record of the evidence hearings held at Parliament on 28th November and 5th December 2017

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1. Introduction

1.1 This is a written record of the evidence hearings that were held at Parliament for the Inquiry into capacity problems in NHS eye care services in England, by the All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment. It is based on notes taken during the sessions and should not be read as a verbatim transcript. The APPG is not able to verify the accuracy of the information provided. Each of the sessions heard spoken evidence in two sections:

* Firstly, from patients who have experience of sight loss and using NHS eye health services; and,
* Secondly, from professionals involved in the provision of these services, including clinicians, commissioners and other interested parties.

1.2 The Chair of the 28th of November session was Lord Low of Dalston, the Co-Chair of the APPG. For the 5th of December session, the Chair for the patients’ section was Jim Shannon MP for Strangford, the Chair of the APPG. The Acting Chair of the professionals’ section was Richard Holmes, RNIB’s UK Parliamentary and Public Affairs Manager, who provides the secretariat for the APPG-Secretariat with Sophie Pavlovic of the Optical Confederation.

1.3 The endnotes in section4 explain key references which speakers made that all readers may not be aware of.

2. Session1, 28th of November

2.1 Malcolm Johnson

2.1.2 Malcolm Johnson lives in the West Midlands. Although beyond retirement age, he is still operating Business Development Management, Training and Systems Services to UK and international companies. He is very involved in the charity the Macular Society, locally leading a support group and nationally as a Volunteer Speaker and working closely with the Society’s Executives in various campaigns.

2.1.3 Malcolm was diagnosed with wet age-related macular degeneration (AMD)[**[[1]](#endnote-2)**] in November 2015. He said he cannot fault the clinicians – consultants and ophthalmic nurses – in their provision of good care; but said he was let down by hospital executives and administrators.

2.1.4 Malcolm said despite international guidelines[**[[2]](#endnote-3)**] stipulating that newly diagnosed wet AMD patients should receive their first of three loading injections within two weeks[**[[3]](#endnote-4)**]; he was told he might have to wait nine weeks. He decided to seek private treatment which cost him £1,800 for three Avastin[**[[4]](#endnote-5)**] injections.

2.1.5 Malcolm was then referred back into the NHS where a consultant planned two injections of Eylea [**[[5]](#endnote-6)**], four weeks on from his last Avastin injection, followed by a second injection four weeks later. The first date came and went, without any communication from the hospital. Malcom said, in desperation he sought help from the Patient Advice and Liaison Service [**[[6]](#endnote-7)**] who secured dates for the injections, although the first injection was two weeks late, from when it should have happened.

2.1.6 Malcolm said his NHS-care is ongoing with reviews with team consultants and receiving injections when considered necessary. He said that despite consultants’ planning forward treatment the administration’s appointment booking processes seemed not to be coordinated with their requests. Malcolm said only twiceinten injections was he given an appointment without having to call and chase up and had to fight for every appointment. Appointments secured at short notice highlighted that the hospital pharmacy requires 48hoursnotice to supply the drug on prescription, causing frustration to both clinicians and himself as a patient whilst at hospital.

2.1.7 Malcolm said he panicked when he was first diagnosed with wet AMD, because he feared he may rapidly go blind, lose his businesses and be unable to drive the long distances required. Initially he said there was a complete lack of quality information and NHS delays caused a huge amount of stress. Private treatment was very costly, but it was a period of calm before the stress and frustration returned on readmittance to the NHS.

2.1.8 Malcolm said a postcode lottery exists in the efficiency of hospital bureaucracy’s management of ophthalmology. NHS decision-makers need to introduce more mandatory time limits and treatment guidelines for wet AMD with effective communication and coordination processes between appointment booking offices and clinicians to ensure patients receive appointments on time. Also, pharmacies should allow ophthalmology clinics to hold stocks of drugs to enable same-day injection treatment to newly diagnosed patients.

2.1.9 Lord Low, the session Chair, asked if the resources are there in eye health, but the administration lets things down?

2.1.10 Malcolm said there should be timescales for appointments for wet AMD. It is crucial for patients to receive their initial and subsequent injections for wet AMD otherwise people can rapidly lose their sight. Lucentis[**[[7]](#endnote-8)**] should be given every four weeks and Eylea should be given every eight weeks. International guidance for timescales are not being followed. Some hospitals are meeting them; but some are not. It is about business competence.

2.1.11 Malcolm said he pushes for appointments, but a lot of people do not, particularly as many are elderly. He said in his region three hospitals are managing to overcome capacity problems by offering same-day treatment and giving people their next appointment when they leave the hospital.

2.1.12 Lord Low asked “what is the effect of not adhering to international timescales?”

2.1.13 Malcolm said when he was diagnosed his visual acuity (central vision) was 6/10. Threedays later it was 6/15 and he was put on a waiting list and told by a principal consultant he might have to wait nineweeks. However, when he went private, within sixhours of having treatment with Eylea injections, all distortion and cloudiness disappeared. Malcolm said that with wet AMD the sooner you give people the injections they have a better chance of halting the progress of wet AMD, and there are lower costs to the NHS.

2.1.14 Lord Low asked how do you know there is a postcode lottery?

2.1.15 Malcolm said through voluntary work with the Macular Society and he has researched the provision of treatment in other areas where it is offered more quickly and consistently.

2.1.16 Lord Low asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

2.1.17 Malcolm said:

1. There should be a greater degree of mandatory time limits which are applied and linked to international guidelines and clinics measured against these.

1. Hospital pharmacies should give eye departments a stock of drugs, so they can do same day treatment rather than the pharmacy only releasing a drug for a named patient which creates much delay.
2. The appointment booking system and staff need to work more closely with staff in the eye department. Patients should not have to proactively ask for appointments.

2.1.18 Malcolm said that recruitment problems mean there is a shortage of consultants north of the Watford Gap.

2.1.19 Lord Low asked is there an additional problem on the medical side, not just problems with processes on the admin side? Does this shortage of clinical staff contribute to problems for the appointment booking side?

2.1.20 Malcolm said yes, although nurses can give injections, some hospitals are slow at training nurses to undertake this role. More consultants are needed; however, this could be helped if more nurses were trained to deliver injections.

2.1.21 Also eye departments need consistent support from hospital admin. A hospital is only as good as its CEO and the turnover of CEOs is very high.

2.2 Catherine Grubb

2.2.1 Catherine Grubb lives in the South West and has glaucoma. In the 1990s she was diagnosed as having Thyroid eye disease[**[[8]](#endnote-9)**] for which she was monitored by appointments every sixmonths, and subsequently for glaucoma[**[[9]](#endnote-10)**], at the eye department at London’s Charing Cross hospital. At that time, when she attended an appointment, the next appointment would be made.

2.2.2 However, Catherine said when she moved to the South West in 2002, the general hospital she attended there extended her monitoring appointments to twelvemonth intervals. In 2013 she was formally diagnosed with glaucoma.

2.2.3 Catherine said that since 2005 she has had to chase up all her appointments and has to make up to five or six phone calls to secure an appointment, for example by calling the consultant’s secretary or the glaucoma clinic. The Consultant Clinic Manager suggested she seek assistance from the Patient Advice and Liaison Service to secure appointments. Catherine said some of her appointments had been delayed by between six to eight weeks; but the worst delay was three months. She said she knows patients in other eye departments who have had far longer delays. Catherine said she does not think the delays have been detrimental to her eyesight as far as she knows.

2.2.4 Lord Low asked what would have happened if she had not contacted the hospital?

2.2.5 Catherine said she was sure that if she did not call she would not get an appointment. She does not like chasing up, but will do it as, although currently stable, her eye health could change. She said some people think the hospital knows best, or do not want to bother them, or lose track of time and call after maybe three months, or maybe completely forget. Some might finally call, but not until they have suffered sight loss.

2.2.6 Two years ago the hospital she attends set up a Glaucoma Clinic to provide a one-stop experience to speed things up. However, she said appointments still need to be chased up and it needs to be more efficient. She said she has only seen the Nurse, she has incipient cataracts[**[[10]](#endnote-11)**] so would like to have access to the consultant so that conditions are not missed.

2.2.7 Catherine referred to the recent Care Quality Commission (CQC)[**[[11]](#endnote-12)**]recommendation that Royal Cornwall Hospitals should go into special measures, and Catherine referenced CQC’s report that it had found four outpatients had suffered very badly from delayed appointments, with one patient losing their sight. Catherine said that maybe problems are due to a large elderly population, poor administration or a lack of staff. She said at one point the hospital lost two consultants at the same time. Catherine was also concerned that if the hospital was struggling over time this could impact upon recruitment with it not being able to recruit the best clinicians.

2.2.8 Catherine said one positive thing has been the optometrist she sees who she said had been brilliant over the years at explaining things in ways no doctor ever has. They have been reassuring and allowed time for questions. Catherine said without this she would be more distressed and depressed than she is.

2.2.9 Lord Low asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

2.2.10 Catherine suggested:

* The hospital’s backlog needed to be cleared-up so that it is not always trying to catch up, by introducing a ‘hit squad’ of clinicians and administrators to bring things up to date and sort out administration
* She would like the APPG to recommend that hospitals provide appointments in advance and then stick to them rather than the onus being on patients to chase
* Hospitals need to introduce an effective appointment system that patients can trust and know what will happen for follow-ups and reminders. For example, like at Charing Cross Hospital in the 1990s which would give patients monthly appointments when they attended hospital and reminders two-months before, as dentist surgeries now do by text or phone.
* The glaucoma clinic had one machine and another machine, and each patient moved along the line. Would it be possible to double up on these to speed up the process through the clinic?
* Catherine would also like to see her consultant more often for advice rather than just getting a letter from a doctor who has looked at her test results, as she feels they will pick up more than those who regularly see her at appointments. She assumes this is due to her consultant just not having the time to see patients so regularly.

2.3 Michael Tupper

2.3.1 Michael Tupper lives in the North West and said he has had eyesight problems since he was very young and was treated with patching as a child. He now has glaucoma, cataracts and partially detached retinas. He was under Moorfields Hospital’s care for 20years and is now under the care of a hospital near where he lives.

2.3.2 Lord Low said “you have a long history of receiving eye care from the NHS. How does the standard of care compare now with the past?”

2.3.3 Michael said things have generally got better. He had negative and positive experiences to relate and a solution.

2.3.4 Michael cited what he said was a negative: he had a problem with an appointment with a consultant for a general check-up and was told to come back in six-month’s time; but was told by the receptionist there were no appointments and they would send a letter. Michael phoned a month before the appointment was due but was told again there were no appointments. Michael said he had to make four or five phone calls before he was finally given an appointment. Michael commented that admin staff either did not know or care enough about what the consequences are for people with certain conditions if they do not get an appointment when they need to.

2.3.5 Lord Low asked are they problems of capacity where there are not enough clinical staff, or the competence of the admin staff?

2.3.6 Michael said he thought both. There are not enough consultants but also the attitude of the admin staff was not good enough. If someone is a bit nervous they probably will not persist; but they will end up at the clinic after a few months, which is likely to cost more in the end.

2.3.7 Michael cited what he said was a positive: in early 2017 he was due for a regular check-up where he was diagnosed as having Chronic obstructive pulmonary disease (COPD)[**[[12]](#endnote-13)**]. He was told by the nurse whose care he was under, that the drugs for glaucoma can cause COPD so they changed his prescription. He went for a yearly check-up with the optometrist on a Wednesday where they checked the glaucoma pressure in his eyes which was found to have gone up to 28 when it was normally between 12 and 14.

2.3.8 The optometrist immediately contacted the Triage Sister and a Fast-Tracked appointment was made and Michael received an appointment letter twodays later for the following Friday. The glaucoma nurse made contact with consultants and tests were done in January 2017 with appointments made there and then. Michael said this had been a positive intervention by the optometrist.

2.3.9 Lord Low asked Michael if his glaucoma pressures have improved?

2.3.10 Michael said he thought so. His optician is monitoring him with whom he has a good relationship. He said consultants are not causing the problems; it is due to capacity problems. He cited arriving at an eye clinic and at 10am it was already announced that they were running an hour late.

2.3.11 He said the problem is that there are too many patients, a shortage of consultants, not enough resource, both physical and staff, and admin staff need more training and expertise.

2.3.12 Lord Low asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

2.3.13 Michael said:

* Shared information regarding risks e.g. for conditions such as COPD
* ‘Ask and Tell’ – the message of RNIB’scampaign, for patients to ask the consultant and tell the booking staff to ensure they get an appointment
* Eye Clinic Liaison Officers (ECLO) and Sight Loss Advisers[**[[13]](#endnote-14)**] – not all hospitals have them, and a lot are sponsored by RNIB. They help steer and guide patients and provide psychological support. They are needed in every hospital to help people
* The Accessible Information Standard[**[[14]](#endnote-15)**] – was introduced in 2016 but has still not been fully implemented in many parts of the NHS. The Standard should be used in all communication because people need to receive information in the format they require. People cannot read a letter which is inaccessible and will not want to show it to someone else which can be embarrassing.

2.4 Bernadette Warren

2.4.1 Bernadette Warren is from the South East and has Diabetic macular oedema (DMO)[**[[15]](#endnote-16)**]. She said she had a few concerns about communication and knowledge within the NHS.

2.4.2 Bernadette said she had a difficult story to tell. She had found the last few years difficult and has felt angry, let down and frustrated at the situations she was going to give evidence about. She said she had decided to take the approach of ‘it would have been better if’ rather than trying to apportion blame. Also, to give an example of an initiative having a positive impact on capacity issues in her geographical area.

2.4.3 By 2011 Bernadette had had type1 diabetes[**[[16]](#endnote-17)**] for 15-years. She had found her blood sugar levels difficult to control. In 2011 she was offered the opportunity to change from insulin pens to an insulin pump and said she grabbed the opportunity.

2.4.4 Bernadette said at this stage her eyes and sight were fine and she was enjoying working and bringing up her children with her husband. She had an OCTscan[**[[17]](#endnote-18)**] in February 2011 which showed both maculas were healthy. In March 2011 she was given an insulin pump. Her blood sugar levels had been quite high for a while, so the Diabetes Team decided to set the pump to reduce her blood sugars down from 15mmls to between 6-8mmls. Her blood sugar levels improved very quickly within the first two weeks and Bernadette said she and the Diabetes Team were very pleased with the outcome.

2.4.5 However, after eightweeks Bernadette noticed her eyesight was not as good as it was, and she just thought she needed new glasses because she was middleaged; but after an appointment at the opticians she was referred to hospital where she was diagnosed with DMO. Bernadette started receiving eye injections in both eyes the following month but said she has given up on her left eye but is still having injections in her right eye.

2.4.6 Bernadette said she had wondered if there was any correlation between starting the insulin pump and the deterioration of her eyesight. She did her own research and said she was shocked to find that lowering blood sugar levels quickly, can have negative consequences on the eyes as the tiny blood vessels can be affected by sudden drops in these levels. She said this information was confirmed by many ophthalmologists she had spoken to.

2.4.7 Bernadette said that it seemed the Diabetes Team had a lack of knowledge about the consequences of a rapid reduction in blood sugar levels upon the eyes which could affect sight. Bernadette said there was a lack of knowledgesharing and consultation between the diabetes and ophthalmology departments. It would have been better if the Diabetes Team had known what could happen with this plan of action or at least shared their plan with an ophthalmologist.

2.4.8 Lord Low commented it was more than just a communication problem wasn’t it? The Diabetes Team should have been aware of what could happen.

2.4.9 Next, Bernadette talked about the registration of sight loss. She said the only person who can sign the Certificate of Vision Impairment (CVI)[**[[18]](#endnote-19)**] at the hospital she attends is the consultant; but it is very difficult to get to see them as they often have their own list of people to see. Bernadette said she could not get an appointment with the consultant for three years who was the only clinician who could sign the CVI; although in the meantime she was seen by a range of other eye health professionals.

2.4.10 Bernadette said in 2015 she felt perhaps her sight was at the stage that she could be registered, so she asked a rehabilitation worker about it who confirmed she could ask her consultant to do this. Bernadette initially asked her GP to write to request an appointment, but this did not work, so she sought assistance via the Patient Advice and Liaison Service to get an appointment with a consultant to sign a CVI. Within a week she had an appointment and was registered.

2.4.11 Bernadette said the gap between sight loss and being registered caused her much stress, not because she could not claim benefits; but because she wanted to be able to tell people she was registered, and so her other sight loss friends and charities would understand the level of her sight loss. She said she wanted to fit somewhere. Not being registered meant she was neither in the fullysighted world or officially in the sightimpaired world.

2.4.12 Bernadette said being unable to get registered did not help her adjust to her sight loss; but once she was registered she was able to move forward. She suggested it would be better if a senior ophthalmologist could sign the CVI instead of having to wait such a long time.

2.4.13 Bernadette had also found access to treatment difficult at times. She had already received 20 injections of the drug Avastin in her left eye before trying to gain access to the drug Lucentis. She said the clinicians and herself were desperate to try this new drug. It had approval from NICE[**[[19]](#endnote-20)**] for AMD but not for Bernadette’s condition, DMO, so she had to carry on with Avastin even though it was not working or have no injection at all.

2.4.14 Bernadette said since she was so keen to try Lucentis she did her own research to see when it might be approved for DMO. She phoned NICE and her own Primary Care Trust[**[[20]](#endnote-21)**]. She found out it was under guidance and then was approved by NICE in February 2013. Bernadette informed her Ophthalmologist who said they did not know how to get hold of the drug.

2.4.15 So Bernadette phoned NICE again who told her to just send a simple email to her Consultant requesting the drug for her condition, and within twoweeks she received her first Lucentis injection and was the first patient at her local hospital to receive it for DMO.

2.4.16 Bernadette said it would have been better if her Consultant had been informed about the availability of Lucentis for treating DMO, so that her treatment could have started sooner instead of, as in Bernadette’s case as a patient, had to find out and waste time.

2.4.17 Next Bernadette talked about a positive example of a mobile macular unit which travels around a number of counties in the South East, which she said has helped her and many other people. Bernadette said it has really helped so many people who can have eye treatments close to home; compared to hospital appointments which can take up to three hours. The mobile unit means that patients who can access the service this way are seen a lot quicker, and there are advantages for people like herself as she does not have transport to get to it, as hospital eye clinics are not as busy, so appointments are quicker. Bernadette said she hopes that more mobile units become available throughout the country.

2.4.18 Bernadette said her life has changed a lot over the last few years and it had not been easy. She lost her job in 2012 after 20 years as a teacher, but said the school were unwilling to adjust. Bernadette said it was one of the most painful experiences of her life and she is still unemployed. In 2013 she lost her driving licence and some of her independence. Bernadette said that sight loss is not just about sight loss; it is about a lot of losses. She said she had to constantly build her self-esteem to live a life she never expected to live. She also said there have been other opportunities and she has gained new skills such as reading and writing Braille.

2.4.19 Bernadette said the hardest thing has been juggling diabetes and sight loss at the same time when she cannot see properly, but she has the support of friends and family and a good team at the hospital. She said there are some new things coming in via the NHS to help with this; but wished there was more help for people with chronic conditions and sight loss to help people manage them.

2.5 Sarah Burns, NHS Durham Dales, Easington and Sedgefield Clinical Commissioning Group, and Jackie Storey and Lorrae Rose at the North East Commissioning Support Unit

2.5.1 Sarah Burns is the Director of Commissioning at NHS Durham Dales, Easington and Sedgefield Clinical Commissioning Group (CCG). Jackie Storey is the Commissioning Support Officer and Lorrae Rose is the Operational Delivery Manager at the North East Commissioning Support Unit. This CCG, North Durham CCG, Darlington CCG and County Durham and Darlington Foundation Trust, submitted a combined written submission to the Inquiry’s Call for Evidence.

2.5.2 Sarah said the Health and Wellbeing Board[**[[21]](#endnote-22)**] for Durham and Darlington, Carolined out a Joint Strategic Needs Assessment[**[[22]](#endnote-23)**] in 2015 for all three CCGs which showed a projected increase in the elderly population to one in four people by 2030. RNIB’s Sight Loss Data Tool indicates a rise of eight per cent in the number of people living with glaucoma in County Durham and six per cent for Darlington by 2030.

2.5.3 Sarah said the CCG also regularly reviews expenditure and outcomes and the ophthalmology spend was high but with not necessarily good outcomes. Sarah said Durham and Darlington have a mixture of rural and deprived inner-city areas, so there is a need for local services as lots of people do not have transport or funding to travel. They saw more demand in Durham for the hospital eye service, where the hospitals are dependent on locum ophthalmologists, than the rest of North East.

2.5.4 Sarah said at the start of 2017, the CCGs and County Durham and Darlington NHS Foundation Trust agreed to work to develop a sustainable ophthalmology service and to deliver more services in the community and they have been working with optometrists. They said to do this the commissioners and the trust have worked together and developed good relationships with the Local Optical Committee Support Unit (LOCSU), the Durham, Darlington and Tees Local Optical Committee (LOC)[**[[23]](#endnote-24)**], and Primary Eye Care North East. Lorrae said the company was established by local optometrists and enables services to be delivered on a larger scale.

2.5.5 Work so far has involved:

* A review of individual pathways within the eye care service, to map the patient journey and understand the number of attendances and procedures for each pathway
* A review of cataract surgery and post-surgery follow-up to bring it into line with the regional average
* A community optometrist who has a Diploma in Glaucoma[**[[24]](#endnote-25)**] was funded by the CCGs to review 6,000 patients on the hospital’s glaucoma register (with support from the Trust’s Clinical System Manager), and identified low-risk stable patients who could be seen in the community rather than in the hospital – now all cases are triaged in the community in the first instance
* A children’s vision screening service in local optical practices which means that if a child is referred onwards after vision screening in school, they can be seen in their local opticians, rather than in the hospital, and
* A demand management system – a triage system ensures GPs make use of available community ophthalmology and optometry before making a referral to hospital eye services, e.g. for the intraocular pressure service and the Community Based Ophthalmology Service, both for all three CCGs, and a Minor Eye Care and Treatment Service for Darlington and Durham Dales Easington and Sedgefield CCGs.

2.5.6 So far, through the work delivered in the community, there has been a 40 per cent reduction in demand on the ophthalmology service in the Durham Dales Easington and Sedgefield CCG-area, and a 12 per cent reduction in attendances in the hospital eye service, and they think this is only going to get better.

2.5.7 Lord Low (Chair) said there is evidence that patients’ access to eye care services varies depending on where they live in England. What do you think needs to be done to ensure this unwarranted variation is reduced? Do you think a national eye care strategy for England would improve the situation?

2.5.8 Sarah said in some instances, variation might be warranted, depending on the different needs of different people. There is higher prevalence of eye conditions in Durham, but that does not explain all variation. In Durham, patients prefer local services. They are looking at utilising the workforce properly and need to ensure an appropriate level of care and to move it to the community where appropriate.

2.5.9 Lord Low (Chair) asked with an aging population and the possibility of new treatments for conditions like dryAMD in the foreseeable future, what do you think needs to be in place to ensure eye care services can cope with increased demand?

2.5.10 Sarah said planning for future demand and resource required specialist analysis and enough trained consultants as well as local services such as optometrists with a Diploma in Glaucoma, to respond to high demand particularly where patients are elderly.

2.5.11 Edward Argar MP (for Charnwood in Leicestershire) asked if, other than increases in patients with AMD and glaucoma, what are the drivers for things going up? Is it demographic or other things? Is it that we can identify conditions and treat better or more awareness? Is it due to the younger demography of patients going up, such as due to diabetes?

2.5.12 Sarah and Jackie said fantastic advancements in treatments were driving demand, as well as patients with eye conditions being referred into the system that need to be seen frequently, so patients stay in the service a long time and are constantly adding to the numbers. They said diabetes is also a huge issue in the local population. There is fragmentation of services which makes things harder. CCGs are not responsible for the full eye care pathway as they commission services for diabetes whilst NHS England commission retinal screening.

2.5.13 Edward Argar MP asked about the CCG’s relationship with the local authority and with industry?

2.5.14 Sarah said they have an excellent relationship with the local authority – it Carolines out the Joint Strategic Needs Assessment which helps the CCG in its planning. They said the CCG have struggled to make contact with industry though. The CCG have a techcompany in their area which has produced a sleep mask for patients with DMO, but it takes a long time for such treatments to be tested and approved by NICE.

2.5.15 Edward Argar MP asked about the shift from acute settings to the community and what the benefit is of delivering services in the community?

2.5.16 Lorrae said that it was early days, but so far so good. The figures from the trust showed a decrease of 12 per cent from acute settings and they could be saving over 100 ophthalmology clinics over a year.

2.5.17 Edward Argar MP asked if they had any statistics or information on: the shift away from acute to community provision; workforce modelling; benefit to the CCG and acute trust, including financial; a risked-based approach; health economics; waiting times and outcomes for patients; and asked them to send this information to the Inquiry following on from the evidence session.

2.5.18 Jackie and Sarah said yes, it is risk-based. They want to make sure the model is not just delaying patients that need to be in hospital, so they are keeping an eye on that. However, it could be freeing up over 100clinics a year. They can benchmark variation across the North East.

2.5.19 Edward Argar MP asked, so using clinics in line with clinical risk drivers is a better way to use capacity, although it does not take away the need to address capacity issues in general?

2.5.20 Jackie and Sarah said the result of employing lots of locums is that the service is operating at a loss. They said they think you need to employ fewer locums and improve recruitment to ensure the service is under less pressure.

2.6 Paul Botts, Vista

2.6.1 Paul Bott is the Chief Executive of Vista, a local sight loss charity for Leicester, Leicestershire and Rutland. Vista sent a written submission to the Inquiry’s Call for Evidence.

2.6.2 Paul said Vista holds the statutory register for the local authority and works across health and social care, and provides:

* rehabilitation and children’s habilitation
* a wide range of communitybased services
* care homes offering 24-hour care, two for people with sight loss and a learning disability and two for older people with sight loss, including a specialist provision for people with sight loss and dementia.

2.6.3 Paul said Vista have very good links with local hospitals and the CCG. Vista:

* host the low vision clinic and
* provide and fund ECLO’s in every eye clinic in the area at: Leicester Royal Infirmary, Coalville, Harborough, Loughborough, Hinckley, Melton and Oakham, and
* fund the only paediatric ECLO in the Children’s Eye Clinic, which is the only paediatric ECLO in England (there is one in Northern Ireland).

2.6.4 Paul said although Vista is an exemplar of good practice and provides marvellous services for people with sight loss, they are not a national organisation, so cannot offer a national perspective on eye health.

2.6.5 Paul said Vista are focussed on the eye health needs of the local population, and because they hold the statutory register for Leicester, Leicestershire and Rutland, they know that as of the 28th of November there are 6,095 people registered as blind or partially sighted from a total population of 1,045,000.

2.6.6 Paul said from the register Vista know that in Leicester, Leicestershire and Rutland, in 2016 they had 58 registrations per 100,000 in the year compared to data from the Public Health Outcomes Framework (PHOF)[**[[25]](#endnote-26)**], which nationally is just 41.9 registrations per 100,000 people.

2.6.7 Paul said from the register Vista also know there was an increase in the previous year in children being registered, 52 in 2015 to 72 in 2016, though they are not yet clear whether this is a blip or the beginning of a trend.

2.6.8 Paul said looking at other metrics on preventable sight loss in the PHOF per 100,000 against the data they hold in the local register for Leicester, Leicestershire and Rutland, for:

* AMD - PHOF data shows 114 per 100,000 but on the local register they have 2,300 for a population of one-million people, an incidence that is twice the national figure, and has grown in each of the previous three years from 1,952
* Glaucoma – nationally it is 12.8 per 100,000 but locally they have 536 people registered which is four-times the national figure, and
* Diabetic retinopathy – nationally it is 2.9 per 100,000 but locally they have 361 which is ten times the national figure.

2.6.9 Paul said either there is an anomaly because of the demography of Leicester, Leicestershire and Rutland; or it may be a more accurate reflection of the level of actual need because of the concentration of services in Leicester, Leicestershire and Rutland. Paul said he thinks the local register they hold shows a more accurate reflection.

2.6.10 Paul said for the APPG making recommendations about what is needed on the future of eye health and visual impairment it is important to start with the right information, and in starting to plan, commission and deliver eye care services, it is important to recognise local variance, using local information to better meet the needs of the local population.

2.6.11 Paul said that is the question asked by the APPG-Inquiry – how can commissioning, planning and delivery of eye care services be improved?

2.6.12 Paul said at the beginning we need to define the term ‘improved’ – is it reaching more people, reducing the number of people losing their sight, being more cost effective? He said this is because there is a current disconnect between meeting increased need and budgetary pressures.

2.6.13 Paul said if it is about reaching more people to reduce the number of people losing their sight, then he would like to put in a call for local sight loss organisations as having fantastic reach into their local communities.

2.6.14 Vista have developed outreach programmes, mobile vision screening, a children’s vision screening programme, app development and run information campaigns on eye health including wet AMD with partners like Novartis.

2.6.15 The primary issue that Vista see in safeguarding people’s sight is encouraging people to get their eyes tested by an optometrist. Most important is to reach communities that are under-served and currently Vista address this through outreach programmes.

2.6.16 Paul said Vista always point people to their optometrists, however for low income families the conversations Vista have had are that optometrists are seen as retailers rather than health professionals, and he said the question he has been asked is why would they go to a glasses shop when they cannot afford glasses?

2.6.17 Vista has outreach programmes in Leicester, Leicestershire and Rutland and what it has seen year on year, is an increase on the numbers of people seen by their ECLO’s in eye clinics over the past three years from 6,000 people to 8,214 in 2016.

2.6.18 Paul said Vista cannot prove cause and effect, but it is an interesting correlation and they believe they are driving a recognition of demand for eye health services.

2.6.19 Paul said on recognising demand, Vista is doing a piece of work around children’s vision screening. In 2013, the UK National Screening Committee recommended that orthoptic-led vision screening should be offered to all four and five-year olds to identify conditions like amblyopia[**[[26]](#endnote-27)**] and prompt access to treatment. This was reviewed by the UK National Screening Committee, Public Health England had published the service specification, and the same recommendation was made again in October 2017.

2.6.20 Paul said Vista understand that children are not being offered this nationally. Whilst provision exists in most areas, around 80 per cent, they think Leicester, Leicestershire and Rutland are one of those areas where vision screening is not offered. So, Vista developed a programme to screen children’s vision in schools as part of a wider education programme, engaging four and five year olds.

2.6.21 Paul said Vista has just launched the programme so is not yett getting the coverage across the 4,500 four and five-year olds across Leicester, Leicestershire and Rutland. But in the Bradford vision screening programme covering 5,700 children in 2011/12, he said Alison Bruce’s research showed a 97 per cent effective screening in schools, 16 per cent referred onto optometrists and six per cent referred through to hospital eye services for follow up. He said six per cent of the 4,500 children in Leicester, Leicestershire and Rutland is 270 children.

2.6.22 Paul said screening is effective, but it should be noted that in the Bradford Study of those referred to hospital eye services, one-third failed to attend even though the children have been identified as needing a follow up. He said this points to something else going on so that people are not accessing health services.

2.6.23 Paul suggested the following recommendations:

1. Recognition of the importance of good data:
* Vista has the reach it does partly because they have the local register
* The data they have is good, and should be better used in planning rather than relying on the widely-used POPPI and PANSI predictive tools[**[[27]](#endnote-28)**], and
* In recognising that if the wish is to better meet real demand, you cannot meet this need until you know what it is and in planning for what comes next in improving health outcomes, it needs to be based on the best possible numbers.
1. Recognition of the variance in local need - the importance of providing a service that varies to meet local need, not homogenous delivery across the country.
2. Recognition that tools already exist to support eye health, like the UK National Screening Committee’s recommendation on children’s vision screening, but it is not being implemented across the country, though it should be. This is also true for the Accessible Information Standard and international standards for wet AMD.

2.6.24 Edward Argar MP asked, you say there are limitations around data, what can we do to get a more robust data set?

2.6.25 Paul said there is no quick answer, but it is important that everyone who needs a CVI is registered. He suggested registration duties should be given to sight loss societies as it is only one of local councils’ priorities, so they do not always do it as well. Also, 130 local authorities collect data and we need to look at all that data.

2.6.26 Edward Argar MP asked about the use of qualitative and quantitative data, and said from your experience, is patient need assessed effectively at the CCG or Sustainability Transformation Partnership (STP) level?[[[28]](#endnote-29)] How does this impact on commissioning and planning of services? How do you feel the patient voice can inform the effective planning and delivery of eye care services?

2.6.27 Paul said there is a local process for STPs to involve patients, but STPs have not used it effectively. Paul said another good example of patient involvement relates to learning disability called the ‘nothing about me without me’ policy. He said the local authority was not so important now in terms of commissioning due to cuts. He cited the threat of a 90 per cent budget cut which became a 60 per cent cut in actual funding for Vista to run the local statutory register. Paul said the reduction in central to local government funding means local authorities must make cuts somewhere. Paul said VISTA has had to find other non-statutory funders for its services.

2.6.28 Edward Argar MP said whatever view you take on STPs, they present an opportunity to look at health services as a whole, but one written response to the Inquiry from industry reported that out of 44 STPs, only three directly cite ophthalmology as a priority service. Do you think this figure is accurate and is it a lost opportunity?

2.6.29 Paul responded that the most noise was coming from long-term conditions, whereas eye health was not being looked at because it is planned care.

2.6.30 Edward Argar MP asked Paul what he thought about the split between acute and community services in Leicestershire?

2.6.31 Paul said he thinks people have grown up thinking hospital is where you go if you have a health issue. There is a cultural challenge to shift people’s perceptions. The first port of call should be that people go to an optometrist or optician, but people need to see them as health services rather than retailers, to get away from what people see as a financial disincentive. Paul said a local professional network had done some work on this

2.7 Alison Davis and Professor Caroline MacEwen, the Getting It Right First Time Programme

2.7.1 Alison Davis and Professor Caroline MacEwen are Joint Clinical Leads for the Ophthalmology Surgery work stream of the Getting It Right First Time (GIRFT) programme, which is funded by the Department of Health and is one of NHS Improvement’s work streams. GIRFT is designed to improve clinical quality and efficiency within the NHS by reducing unwarranted variations.

2.7.2 Alison is a Consultant Paediatric Ophthalmologist at Moorfields Eye Hospital, Divisional Director for Moorfields South and the National Clinical Advisor for Ophthalmology. Caroline was President of the Royal College of Ophthalmologists (RCOphth) from 2014-17, is a Consultant Ophthalmologist at Ninewells Hospital in Dundee, and the Ophthalmology Specialty Adviser to the Scottish Government.

2.7.3 Lord Low commented they will have visited a lot of ophthalmology departments.

2.7.4 Alison gave an overview of the GIRFTProgramme which is looking at tackling variation in outcomes across 35 clinical specialities, with ophthalmology being a key area. The ophthalmology review began in January, and they plan to visit 120 hospital eye departments and have so far visited 90.

2.7.5 Alison said before each GIRFTvisit, Hospital Episode Statistics[**[[29]](#endnote-30)**] data is sent to eye departments, so they can benchmark how they are doing. The visit involves a two-hour conversation about the data, including whether any variation is warranted or not, a Q and A session with hospital staff, and after the visit, the department are given four actions to help them improve.

2.7.6 Referring to cataracts for which there are 400,000 operations each year, Alison said GIRFT’s findings so far include that:

* there are generally very good clinical outcomes
* but there is significant variation in access to treatment
* variation in the eligibility criteria for surgery in different areas, and
* variation in the efficiency of the number of operations of between five to twelve that are performed in each fourhour session.

2.7.7 Alison said they are continually talking about how to improve best practice. One good example they have seen is a dedicated nurse that stays with the patient throughout their journey which improves the patient’s experience and patient flow.

2.7.8 Alison said it also seems that where staff work well together, and clinicians work shoulder-to-shoulder with management, there are better outcomes, and the real test is how much patient involvement there is. The best departments can tell you about the Friends and Family Test[**[[30]](#endnote-31)**] data relating to them; but where they are not so good the data is not available.

2.7.9 Caroline is looking at work that could be done in the community.

2.7.10 Caroline said there are eightmillion NHS ophthalmology appointments a year and 50 per cent are for long-term conditions. They referred to the British Ophthalmological Surveillance Unit study (which she co-wrote) that found between 15 to 22 patients were losing their sight per month[**[[31]](#endnote-32)**]. Caroline said she recognises there is a capacity issue.

2.7.11 They said one of the causes is that new patients are prioritised over review patients, despite the latter being more at risk of losing vision, because there are no ‘Referral to treatment’ targets for them[**[[32]](#endnote-33)**].

2.7.12 Caroline said capacity is currently being addressed by:

* Increasing the workforce but this is easier to address in London than other areas
* Staff are working late and at weekends over and above the hours in their job plans, meaning they are tired, and
* Any Qualified Providers (AQPs)[**[[33]](#endnote-34)**] are picking up extra work but they are destabilising eye departments because they are selecting easy cases, leaving NHS hospitals with the more difficult cases and making it difficult to train people.

2.7.13 Caroline said GIRFT is looking at new ways of delivering care and referred to a model of multiple professional teams as recommended by the RCOphth’s “The Way Forward”[**[[34]](#endnote-35)**].

2.7.14 Caroline said they are working with trusts to look at how to reduce the number of people going to hospital for conditions such as glaucoma and to reduce the diabetic referral rate by about 50 per cent. But the challenges are a lack of space, personnel and IT, with things not networked as they should be. They said there needs to be better use of scanners and OCTs.

2.7.15 Caroline said they are looking at how to improve patient-flow such as by using virtual clinics which need fewer rooms, more patients can be seen and how to get patients to arrive on time.

2.7.16 GIRFT is working with trusts on delayed follow-up appointments, and whether they have the mechanisms to detect if patients are falling by the wayside and if they know whether patients are having their appointments delayed. Some hospitals record specific numbers of these, some do not. They said 76 per cent of trusts have people waiting beyond recommended waiting times and the figure for glaucoma patients is 82 per cent of trusts, so lack of data is key.

2.7.17 Through GIRFT, Caroline and Alison have identified a huge desire for change but there is not enough staff and space and IT is a barrier to change.

2.7.18 Lord Low said the speakers from Durham Dales Easington and Sedgefield CCG and the North East Commissioning Support Unit, had introduced the concept of warranted and unwarranted variation. What are the main dimensions of warranted and unwarranted variation?

2.7.19 Caroline said warranted variation is the ability to effectively manage patients within the timescales; whereas unwarranted variation is not being able to. So operating time may be wasted if there are not enough staff and if resource procurement has not been good enough. Caroline explained that the RCOphth’s “The Way Forward” set out different approaches to take depending on your need. Procurement is still a huge issue though and there should be much more control.

2.7.20 Lord Low asked if GIRFT make recommendations to hospital eye departments?

2.7.21 Alison said GIRFT make four recommendations at each of their visits to eye departments. The power of the deep dives is that they bring together clinicians and hospital executives. They hold follow-up meetings at which executives and clinicians are expected to attend.

2.7.22 Lord Low said what he has heard from patients seems to be more to do with inefficiencies in the administration rather than clinical practice, such as problems booking appointments.

2.7.23 Caroline said the loss of review patients in the system was an administrative issue where nobody is keeping an eye on how many patients are waiting and for how long, and a lot could be learned to improve administration.

2.7.24 Alison said ophthalmology is a very busy specialism and nationally accounts for eight per cent of NHS outpatient appointments. She said workplace stability is important for management, admin staff and clinicians, and they need to work together effectively. Admin staff are important, but they are often easily gotten rid of so that clinicians end up doing the admin work when they are trained to do clinical work. GIRFT hospital visits are also attended by data and finance analysts as well as clinicians.

2.7.25 Edward Argar MP referred to his former role as a management consultant, and asked how well trusts, providers and commissioners understand the risk profile and inform and educate people on where to go so they will be directed to, or be able to self-direct themselves to the right part of the eye-service?

2.7.26 Caroline said it is complex and varies. More work is done in the community in Scotland and Wales which is planned on a national level, and a system has been introduced so that people do not go to their GP now with eye conditions, but instead go to an optometrist. Work in the community requires training of optometrists. The tariff system blocks change as the new patient tariff is sixty per cent greater than for review patients. There are both cultural and risk challenges.

2.7.27 Alison said there are opportunities with STPs to look at optometry services across wider areas. Hospital trusts might cover two CCGareas which can cause confusion. GIRFT are trying to get people to implement best practice such as the “The Way Forward”.

2.7.28 Edward Argar MP said, so tariffs are driving behaviour and we need to be cognisant of this. There are opportunities and potential around new technologies and new treatments, will they alleviate capacity issues or fuel demand?

2.7.29 Alison said it was a bit of both. With virtual clinics there are lots of opportunities to manage demand and you do not have to have a face-to-face consultation unless that is what the patient requests. But once you get a new piece of equipment it increases demand. There is increasing demand and we cannot keep doing more of the same. We will not be able to keep up without embracing change

2.7.30 Lord Low asked ‘from your experience, what do you think the Inquiry could recommend to the Government and NHS which would address capacity in eye care services to make sure all patients receive the care they need?’

2.7.31 Caroline and Alison said:

* Workforce – you need to look at the staffing structure and training and the community
* Where services are delivered – hospital or community settings, not everything should be in an acute setting
* Better IT for patient records, and
* You need to measure patient outcomes including the follow-up of patients and to avoid treatment delays, so that information goes up to the trust board for example for glaucoma patients and if they are at risk then action is taken.

2.7.32 Lord Low asked if GIRFT would be issuing a national report?

2.7.33 Yes GIRFT will be producing a national ophthalmology report in Spring 2018.

3. Session-2 on the 5th of December

3.1 Malcolm Bigg

3.1.1 Malcolm Bigg lives in the South East, is retired and a patient representative for his local CCG and has diabetic retinopathy[**[[35]](#endnote-36)**]. Five-years ago he was suspected to have detached retinas. This turned out not to be the case, but he was given three days of laser treatment. He said this made him feel wary. An optometrist referred him to hospital via an admin company. He waited 18 weeks although his condition was urgent as the hospital decided it was not urgent and downgraded his referral. After 20weeks he spoke to the doctor and was told the hospital did not have anyone who was qualified to deal with his eye condition.

3.1.2 Malcolm said he was then referred to a different hospital – six-months on from the initial diagnosis. He was given an appointment for the 6th of September, but on the 4th of September received a letter saying his appointment had been moved to the 24th of September, at the original hospital which he was told now had appropriate staff. Malcolm said that was when he queried the delays and was told he should have progressed this earlier and was subsequently told there was nothing wrong with his eyes.

3.1.3 Malcolm complained to his CCG, but it responded they could not find anything wrong with the system, although they apologised. Malcolm challenged this but was told because there is a waiting time of 18 weeks the CCG do not make and tell you about your appointment; instead they wait to make your appointment during the last four weeks (of the 18 week-period).

3.1.4 Malcolm said this is not a good system. He said by this point you will have made plans. Why can the appointment not be made in advance? He said they obviously had a staffing problem when he was due to have his appointment. He asked what would they do in an emergency?

3.1.5 Malcolm said there are not enough clinical staff and he has sympathy for them, but systems should be set up to meet patients’ needs not the clinical staff.

3.1.6 Malcolm said there is a problem when different hospitals make appointments and you have to complain to different CCGs. When two CCGs are involved they are not taking responsibility. Malcolm said this week [beginning 4th December 2017] he had just received a CCG’s-response to a complaint he made in June 2017. He said the situation may get worse with further reorganisation under STPs.

3.1.7 Jim Shannon MP (Session Chair) referred to Northern Ireland where things go through a patient’s GP.

3.1.8 Malcolm said the optometrist can refer you directly and may classify you as urgent; but the hospital may downgrade you without seeing you, without triage, overruling without consultation with the optometrist.

3.1.9 Jim Shannon MP asked what are the key thing(s) that would improve your experience of treatment and care?

3.1.10 Malcolm said for the hospital to give patients appointments as soon as they receive a referral. This is particularly important for people who may be worrying and wanting to know what is going to happen.

3.1.11 Jim Shannon MP asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

3.1.12 Malcolm said more money to employ more staff. He has no complaints about staff that do an excellent job.

3.2 Christine Wall

3.2.1 Christine Wall is a retired accountant living in East Anglia, still very active in her husband’s business. For five years she was a Lay/Patient representative for the RCOphth and for two years was Vice-Chair of the Patient/ Lay committee of the Academy of Medical Royal Colleges.

3.2.2 Christine said she has had poor eyesight all her life, has had two cataract operations, two Yag laser capsulotomies[**[[36]](#endnote-37)**] and has glaucoma.

3.2.3 Christine said in giving evidence she was speaking from two sides: struggling with her own eye condition; and getting messages across on behalf of patients in the ophthalmology world.

3.2.4 Christine said it is very wrong to think of eye problems as only affecting aged people, not that they don’t deserve good care. From recent experience she gave her view of what the issues are.

3.2.5 Christine said eye problems differ from other medical problems, in that when your eyesight fades or fails, everything about your life is affected detrimentally. It is very hard, impossible to work, train, drive, use a p.c., read and write and maintain dignity and independence.

3.2.6 Christine said since April 2017, NHS Tariffs in secondary care are reduced for follow-up rather than new cases. A change which she says was introduced without any public or patient consultation, despite the Department of Health’s own ruling that patients should be involved in health care decisions. Christine said this impacts very detrimentally upon glaucoma patients such as herself who need regular monitoring if serious further damage is to be avoided.

3.2.7 Christine said the procedure for referrals to the laser clinic is now outsourced to a healthcare provider under an AQParrangement. Christine said she discovered too late that her referral judges her as “Routine priority”; yet her sight had deteriorated in a very few weeks so that she could not drive or read. Christine said it certainly felt extremely “un-routine” to her. She said she was also later informed that more serious eye problems had not been excluded when she initially attended the AQP’s optometrist.

3.2.8 Christine said she had experience of being referred to a local hospital provider under an AQParrangement for her cataract operations. She said while this may be seen as a method to reduce waiting lists; it impacts upon provision of training for junior ophthalmologists since training is not built into AQPcontracts. Christine said it poses significant difficulties for patients like herself who run into post-operative problems since AQPs are not obliged to provide emergency care to their post-operative patients.

3.2.9 NICE, the General Medical Council (GMC) and royal colleges depend on clinician involvement to promote patient care and train the next generation of eye health professionals. Christine said that health trusts are increasingly refusing to release doctors for these important duties and have totally ignored a recent letter from NHS Medical Directors and the President of the GMC, emphasising the importance of such activities. Christine said the latter has expressed concerns that time allocations for trainers to devote to training are under constant and serious erosion. Christine said this will impact on future patients.

3.2.10 Christine said lengthy delays in being seen by a consultant are difficult to accept. She said personally, in the last year she had to wait from early December 2016 until the end of May 2017 to be diagnosed with glaucoma and begin treatment, despite two optometrists having identified what she described as her ‘dodgy optic discs’. She said from reporting sudden severe sight reduction to her optometrist and GP in April, her NHS hospital assessment was not until 26 June 2017.

3.2.11 Christine said that she thinks in East Anglia part of the problem is because the service is outsourced to a healthcare provider under an AQParrangement. Her referral was classed as routine. To her it felt very un-routine. She was later informed by the hospital that optometrists had not ruled out more severe eye problems at the stage when they marked her referral as routine.

3.2.12 Christine said she has serious concerns about the introduction of commercial interests into eye care. In East Anglia, she said GPs have been omitted quite deliberately from the NHS eyecare picture. Christine said she sought advice about the worth of costly “extra” eye tests being suggested by the high streetoptometrist. She said her senior GPpartner informed her in April that he could do nothing to accelerate appointment dates, and said letters to the local hospital eye clinic are returned unread.

3.2.13 Christine said her message for decision makers is simple:

* More resources must go into eye care and into those institutions which have a track record of effective eye care, and
* As a patient she wants her eye care to be under the clinical governance of an NHS consultant. She said she realises she may not see them at each visit, but she needs the reassurance that a senior doctor has oversight of her care.

3.2.14 Jim Shannon MP asked what are the key thing(s) that would improve your experience of treatment and care?

3.2.15 Christine said when she gets to see an ophthalmologist her eye care is excellent; but the journey getting there is the problem. She feels concerned that optometrists are not seeing her condition as more than routine. She said it is about resources, a lot goes into training a good and caring ophthalmologist. She also said there is a need to think about the physical space and resource in eye care and said the eye clinic she attends is like Piccadilly Circus.

3.2.16 Jim Shannon MP asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

3.2.17 Eye care is not just for the elderly it is about getting people of any age back to where they need to be in life, such as school or their exams etc.

3.2.18 Nigel Evans MP (for Ribble Valley) referred to his constituency and the experiences of some visually impaired people getting around the built environment as well as eye care services, and asked has the situation always been bad or is it getting worse?

3.2.19 Christine said she had a broken finger as she fell over as she did not see the kerb.

3.2.20 Malcom Bigg said five years ago the situation was much better. He said a healthcare provider under an AQParrangement was also the same one that delayed his appointment. He said they need more staff. He also said the grading of clinical need of patients is difficult but some people are falling down the list and by that time it is too late.

3.2.21 Christine said the situation has been made worse by the new NHStariff. The problem is that someone other than the consultant is making decisions about priorities such as the hospital administration.

3.2.22 Nigel Evans MP asked is the issue that noone is listening to patients as customers?

3.2.23 Malcolm Bigg said yes they are not being honest about the fact that there are not enough staff.

3.2.24 Christine said the NHS are using AQPs to buy-in extra capacity into the hospital system such as to get lots of routine cataract appointments done quickly. She said the problem is that they do not train junior ophthalmologists as this is not built into the contract. She also said it can be very difficult for patients who have post-operative problems as it can take ages to get to see anyone. She said this happened to her and she had to go private.

* + 1. Derek Thomas MP (for St Ives) said:
* he has done work in the community to look at care pathways, and that research funding for eye health is very low and needs to be looked at
* people are not choosing ophthalmology as a career choice and he has had a discussion with a Government Health Minister about how incentives can be created for people to do so
* he had done a research project trying to feed into the process of formation of the STP in West Cornwall, including optometrists and GPs, which found that optometrists might provide relevant capacity and clinically might have greater expertise in diagnosing eye conditions and feeding into the eye care pathway, and
* opticians and GPs both felt this to be the case and there is a need for patients to recognise this and have confidence and be signposted to optometrists as part of the pathway.

3.2.26 Derek Thomas MP asked what are patients’ views on that?

3.2.27 Malcolm said his optometrist is very highly qualified, but the problem is with someone downgrading the optometrist’s clinical viewpoint. Malcolm said when he has raised this he has been told “well they’ll all say it’s urgent”. He said there needs to be a better system and criteria for urgency and the optometrist’s opinion should not just be overruled. He said there is a lot of patient volume on the high street which is not all going to be seen at the hospital, and there needs to be a better relationship between the NHS and high street optometry.

3.2.28 Christine said the amount of ophthalmology taught in medical schools is very variable which has implications for people choosing ophthalmology as a career. She referred to a medical licensing assessment to give a consistent examination which she said has been suggested by ophthalmologists.

3.3 Elaine Shaw

3.3.1 Elaine Shaw said she agrees with what Christine and Malcolm said – once you get there the eye clinic staff are wonderful and go above and beyond.

3.3.2 Elaine lives in the West Midlands and has myopic choroidal neovascularization (CNV)[**[[37]](#endnote-38)**] which she said if left untreated affects the macular and central vision and requires the same treatment and injections as AMD.

3.3.3 Elaine said twoyears ago she started on Lucentis injections which has only just been licensed for her condition even though the drug has been available for fiveyears, because each drug is licensed separately for each condition. Elaine said that because fewer people have her condition, people with it will always be last in the queue because there are fewer profits, and CCGs can make the decision not to treat them.

3.3.4 Elaine said she had 18 months of Lucentis injections, but her eyes stopped responding to it, and thought she would be switched onto another drug called Eylea as happens for AMD and is available for her condition in Scotland and Wales.

3.3.5 Elaine said she was told her eyesight was too good to treat with Eylea, and said that a ‘too good to great’ rule exists in NICE guidance. She said she made enquiries and found that in England for AMD the NICE guidelines say eyesight needs to have gone down to 6/12 – which is when you cannot drive – before you can get treatment. Elaine said she checked and found this does not apply to her condition myopicCNV. She said this is serious, preventable sight loss, not just a bit of blurred vision, and without the drug she would lose her sight quite quickly.

3.3.6 Elaine referred to a friend called Chris Thorley who had the same experience, and how they have both campaigned through the Macular Society to get NICE to change the rules so that Eylea is available for myopicCNV. Elaine said Chris had to put in an Individual Funding Request (IFR) to the CCG and waited ten-months and received no reply but lost lots of his sight in that time. Elaine said she was told that submitting such a request would be a waste of time.

3.3.7 Elaine said her MP Ian Austin had raised an Oral Parliamentary Question regarding whether a GP should be able to give access to Eylea, but the Health Minister’s answer was that an individual case must be exceptional and unique, and a costing plan has to be worked up to justify treatment for a group of patients.

3.3.8 However, Elaine said she had also been told her consultant should just apply for an IFR. She said her CCG said an IFR is a way for a consultant to make the case that your case is unique. Elaine said consultants do not have the time to make a business case, and the CCG had told her that if something is being considered by NICE then CCGs will always wait for NICE’s decision because they do not want to set a precedent for the NHS.

3.3.9 Elaine said this is blinding people on mass on the basis of cost savings. She said that local commissioners are not commissioning; they are waiting to be commissioned nationally. Commenting on what she said would be the amalgamations of CCGs to make savings of scale under STPs, Elaine said you would not amalgamate two special measures schools to get a better school. She said they need instead to follow those who are putting patients first like in Manchester.

3.3.10 Elaine said she thinks the situation with Eylea will happen again and again for rare conditions such as myopicCNV when new treatments become available, with patients being at the end of the queue.

3.3.11 Jim Shannon MP asked what are the key thing(s) that would improve your experience of treatment and care?

3.3.12 Elaine said central commissioning. She said there is no difference between the needs of patients in different parts of the country, and if CCGs are not putting patients first, then there should be centralised commissioning which puts patients first.

3.3.13 Jim Shannon MP asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

3.3.14 Elaine said seek out the few providers who are doing things well, even though it means acknowledging that upfront cost savings are not the answer. She said spending money might save more.

3.4 Christine Ramos

3.4.1 Christine Ramos lives in the West Midlands and has diabetic retinopathy. She gave some background of her families’ medical history. She was diagnosed with diabetes in her late twenties and said apart from other health complications this led directly to her diabetic retinopathy.

3.4.2 Her father had a physical accident which she was told led to his diabetes, but she said she soon realised that her father’s family were all diabetic as soon as they reached adulthood.

3.4.3 Christine said diabetes destroys the eyes from the back. It causes the problem to creep up unnoticed for a little while unless another physical ailment crops up in the meantime and then a link can be made, and treatment started.

3.4.4 After several years of treatment by tablets she was then put onto injections. Christine said the surgeon explained what was going to happen; throughout his speech she was terrified and in his very last line he said, “you will not feel a thing”, and she told him you should have started with that”.

3.4.5 Interspersed with the tablets, she also had laser treatment which she said she regrets. Christine said you are told about some damage that could be caused to the eyes by this treatment, but realistically there will always be some damage caused because of the nature of laser.

3.4.6 Christine said she was told severe damage could be caused but really damage was always caused. She was later told this by an optometrist when she went for glasses. She said the language that clinicians used was too nonchalant. Christine said she trusted the NHS and did not take their advice too seriously. She said no alternative was offered and communication should have been clearer. She said she has decided not to have any more laser treatment.

3.4.7 Christine said she has mostly received very good treatment from her health professionals. She said she now receives treatment at a purposebuilt facility at a local hospital, which she finds very reassuring because only eyes are dealt with there because there are no distractions.

3.4.8 Christine said you have to be able to trust your medical professionals because sometimes constraints, resources, lack of staff and language used are not explained as clearly as they should be. She said when dealing with something as delicate and important as eyes it has to be totally transparent to all the patients.

3.4.9 Christine said after some treatments she was given an information sheet which she may have read but never actually really understood and she suspects she is not alone in this. She said her diagnosis said her eyes were unresponsive to laser treatment which was not correct, and she refused treatment.

3.4.10 Christine said some things are not explained as well as they could be. To illustrate this Christine read out one of the information pamphlets which she has been given which uses a large amount of medical jargon and which she had found very difficult to understand. Christine said that the term ‘harm’ may be being used in such a way that it becomes normalised every day in the NHS.

3.4.11 Jim Shannon MP asked what are the key thing(s) that would improve your experience of treatment and care?

3.4.12 Christine said the treatment she receives at her local hospital always feels very good as they have a purpose-built facility and open clinic that is there every day and an award-winning team which only deals with eyes, and this model should be rolled-out to all medical facilities.

3.4.13 Jim Shannon MP asked, from your experience, what do you think the Inquiry could recommend to the Government and NHS which could address capacity in eye care services to make sure all patients receive the care they need?

3.4.14 Christine said it comes down to funding. She said diabetes is a growth industry and needs to be looked at more seriously. Sight is the sense that we use the most.

3.4.15 Derek Thomas MP said:

* the issue of STPs and costs and how STPs are not just about CCGs being brought together but also reorganisation which is integrating health and social care
* there will be increased costs for social care if patients do not get health treatment, but if STPs work well they could address some of the issues
* the Inquiry needs to recognise the ‘Get it Right First Time’ principle which leads to cost savings to social care and people’s lives and quality of life, and said “Shaping our Future”, the Cornwall and Isles of Scilly Health STP[**[[38]](#endnote-39)**], has one CCG and the Inquiry needs to be careful what it recommends, and he suggested it could recommend assessing the cost if the NHS does not treat.

3.4.16 Elaine said she had discussed with the Macular Society’s CEO how NICE assess the costs of sight loss when considering authorising treatments, and how they use questions – such as “can you feed yourself?”, “can you walk 100yards?” – which she said do not assess the real cost of sight loss. Elaine said the ‘too good to treat’rule is barbaric. She also eye charts do not always tell the whole picture as they are not always in the same lighting conditions as when reading eye charts, so you cannot always see that well.

3.4.17 Christine Wall said sight is the sense that people fear losing the most. She said people lose confidence when they lose sight, and this is constantly under-estimated. Christine Wall and Elaine both talked about not feeling confident to go out without a companion having experienced sight loss.

3.5 Fiona Spencer, Manchester Royal Eye Hospital

3.5.1 Fiona Spencer has been a Consultant Ophthalmic Surgeon at The Manchester Royal Eye Hospital since in 1998 and specialises in glaucoma and adult cataract surgery. She is a member of the Expert Panel in Glaucoma for the College of Optometrists, and a regional representative to Council of the RCOphth.

3.5.2 Fiona said glaucoma is an asymptomatic condition[**[[39]](#endnote-40)**], so it might not be noticed until it is too late, and patients generally do not know there is a problem unless it is picked up when they see an optometrist. She said people experience issues due to their sight being more prone to falls, it can slow down reading and a person has difficulty finding things in the cupboard. She also said there is no cure so people with the condition are long-term patients. There will potentially be a 44 per cent increase in the number of glaucoma patients from 2010 to 2035.

3.5.3 Fiona said in her clinic there are three consultants overseeing 13,500 glaucoma patients. She said she had seen a change over her time practicing, from when she was a trainee, patients were more likely to have lost vision when she saw them; but now more of a person’s sight can be saved, but this had led to an increased workload. She said it is a workforce issue making it difficult to recruit staff and she thought there would be an avalanche of patients to treat in the future.

3.5.4 Fiona had devised a system that manages and separates patients into groups based on risk of losing their sight. Each team member has responsibility for each patient group.

3.5.5 In 2000, Fiona established a glaucoma pathway which includes an optometric clinic and manages approximately 45 per cent of the caseload.

3.5.6 Fiona also introduced an enhanced referral service in Manchester following engagement with local NHS-systems and the Local Optical Committee. The service is based on an urgent triage system where patients are urgently referred to hospital if their conditions mean they are a priority; whilst people with less urgent conditions are dealt with on a routine basis. The pathway includes an optometric clinic which manages approximately 45 per cent of the caseload. The system is based upon good information. Forty per cent of patients that would have been referred to the hospital turned out to be false positives, so they could be seen earlier and reassured instead of going to hospital. The service has resulted in a low referral rate to the eye clinic at Manchester Royal Eye Hospital.

3.5.7 Fiona said patients are very happy with the service they receive in the optometric clinic. The patient satisfaction survey showed 96 per cent were happy with the service, and 52 per cent rated the service as good, or better than being seen by a consultant.

3.5.8 Fiona said people are better able to adhere to drugs and treatment when they understand their condition, such as in the case of glaucoma. The hospital introduced a programme to train a number of optometrists in glaucoma. However, Fiona said once people get specialist training they may be poached. The programme also teaches nurses how to use instruments to check patients’ glaucoma pressures at home; but Fiona said the CCG does not pay for this so staff have to do things in their own time. Fiona has got nurses involved to help them understand how to speak to patients, to help them in dealing with patients, for example, in explaining how to use their drops. Nurses now run a course of two afternoon sessions for patients to help them understand their condition, called “Get a Grip on Glaucoma”. Fiona said the training of optometrists takes place in the evenings, after work hours, and is unpaid.

3.5.9 Fiona said since 2000, at clinics during the day, glaucoma pressure measurements have been taken by nurses and low risk patients are seen in virtual clinics. She said this has led to an increase in the number of patients that can be seen across the service. Now 45 per cent of patients are seen in the optometric service, 45 per cent of patients are seen in the consultant service, and the remaining ten per cent in the virtual clinic. The lowest risk patients are seen in virtual clinics as are field tests in the community. Fiona said consultants can review twenty of these and test results in the time it takes to see 10-12 patients face to face. She also said the hospital has very good relationships with community optometrists.

3.5.10 Fiona said despite this there can still be planning problems, but these services can help with a backlog. She said the virtual clinic can take measurements and enable ophthalmologists to see more people and make useful interventions, so that by the time patients come in for a face-to-face appointment, they may have made some progress, rather than being left concerned they are not being followed up. She said the service was developed because there are not enough ophthalmologists.

3.5.11 Fiona contributed to RCOphth’s “The Way Forward” project which identified good examples on how to manage increasing patient demand. She said they have learnt that accrediting the team and ensuring there are the right people in the team, is really important for different eye health professionals. In this case, optometrists have been encouraged to become accredited with the College of Optometrists’ Diploma in Glaucoma which is also open to other health professionals.

3.5.12 Fiona has undertaken an extensive audit since 1999 which has been published to demonstrate the outcomes of the service and learnt where the easiest wins are that can be made, and which can be shared with other areas.

3.5.13 Richard Holmes (the acting Chair for this session), said it seems like there may be a postcode lottery and it sounds like Manchester is a very clear and successful model. What interest is there from others in sharing these practices? Should there be a national strategy?

3.5.14 Fiona said not necessarily. There are geographical differences e.g. rural and urban and some differences and it is difficult to mirror services. What staff are available also needs to be taken into account when shaping services. She said in Manchester they have worked a lot with optometrists whereas some colleagues have worked with nurse practitioners. She said what is needed is a competency framework rather than a particular health professional, and it is more about demonstrating what you can do than where you started from.

3.5.15 Fiona said they were in a privileged position in the Manchester area because the management team support clinicians well. She said she had heard from other colleagues that it can be difficult to get CCGs’ buy-in for eye care services.

3.5.16 Richard Holmes asked, regarding the service at Manchester on educating patients, has the importance of this been understood by hospital colleagues?

3.5.17 Fiona said the model emphasises things to patients in terms they can understand. Consultations from other areas come and visit to do the “Get a Grip of Glaucoma” course. However, she said staff are not funded to do it and it is provided ‘on a wing and a prayer’. Fiona said they wished commissioners understood that patient education would mean fewer visits to eye clinics. She also said she had learnt from participating in groups from patients about how she could explain things more clearly to them about their condition.

3.5.18 Richard asked what do you think the Inquiry could recommend to the Government and NHS which would address capacity in eye care services to ensure all patients receive the care they need?

3.5.19 Fiona suggested developing a partnership with patients – when commissioning services it is very important to get feedback from patients especially about what is not working.

3.6 Prab Bopari, Optometrist in Wolverhampton and Chair of Wolverhampton Local Optical Committee

3.6.1 Prab Bopari is an optometrist who runs her own independent practice in Wolverhampton, works part-time as a hospital optometrist at Wolverhampton Eye Infirmary, and is chair of the Wolverhampton Local Optical Committee.

3.6.2 Prab said there is growing demand on the hospital eye service, citing RNIBfigures of 8.2 million ophthalmology appointments in 2015/16, the second highest reason for outpatient appointments by specialty.

3.6.3 Prab cited RNIB figures that in 2013 the total cost of sight loss to the UK economy was £28 billion, with £3 billion spent on eye care services and £25 billion being indirect costs. Prab also cited the RCOphth’s estimate that the number of ophthalmologists is unlikely to rise. However, she said a 22 per cent rise in glaucoma is predicted over the next tenyears and by 44 per cent over the next 20 years. Prab said there is a need to reduce eye hospital appointments especially for early detection and monitoring of conditions like glaucoma, diabetic retinopathy, AMD, cataracts, Accident and Emergency (A&E) and children’s eye care.

3.6.4 Prab said the current GOSmodel[**[[40]](#endnote-41)**] is outdated because it leaves patients with no alternative to accessing care via the hospital eye service, and it is where optometrists must refer them to. She said it also does not allow funding to do extra tests. She said community optometry can bring appointments closer to home. Prab said patients are often afraid of hospitals, so they may delay going for eye exams until a serious condition is present at a later stage, such as cataracts and glaucoma, which may involve a higher treatment cost. She said early detection and treatment is key to avoiding sight loss, reducing costs and can lead to higher quality of life for the patient.

3.6.5 Prab said hospital optometrists and GPs are already managing many conditions such as post-operative care and stable glaucoma. She said there is a need to look at what other resource is available in the primary sector to release capacity in secondary care. Prab said optometrists are subject to General Optical Councilregulated training and are equipped to carry out most eye care services that are Carolined out in secondary care. She said early detection and treatment is key for patients.

3.6.6 Prab said in Wolverhampton the CCG recognised the potential of local community optometrists. In 2014, the CCG commissioned three community extended eyecare services in Wolverhampton: a Minor Eye Conditions Service (MECS), an Intraocular pressures referral refinement service and a cataract pre-assessment service. Prab said the introduction of these services depended on effective collaboration between ophthalmologists from Wolverhampton Eye Infirmary, Wolverhampton CCG and the Wolverhampton Local Optical Committee which represents service providers. The Local Optical Committee Support Unit (LOCSU) and the Heart of West Midlands Primary Eye Care Company also supported the new services to be set up.

3.6.7 Prab highlighted the MECS which aims to direct patients with sudden eye problems to a local accredited optometrist, who will triage the presenting symptoms and offer an appointment time according to how serious they are. Prab said its benefits are:

* Patients like the service because it is more convenient being local, provided in nonhostile surroundings that are often known to the patient, which reduces patients’ anxiety
* It provides high quality out-of-hospital care with less waiting time compared to the A&E department and reduced appointments in an overburdened A&E
* Direct and timely referrals for further treatment if needed
* Reduced unnecessary referrals to the eye clinic, and
* Reduced CCGcosts – a MECSappointment costs £60 compared to between £120 to £150 for the A&E department and a follow-up appointment of around £50.

3.6.8 Prab said MECS provides clinical effectiveness with a reduction in hospital attendance and very high patient satisfaction.

3.6.9 Prab said collaborative audits were Carolined out to assess the service performance and seek ways to improve quality standards, and showed benefits for providers, commissioners and patients. She said:

* It led to Wolverhampton CCG recommissioning all three community extended eyecare services
* Audits found most patients, up to 80 per cent, attending A&E with an eye complaint did not need to be seen or treated in hospital
* Up to 60 per cent of patients could be seen and managed in the community, saving hospital time and money
* Since MECS was started in 2014 there has been a 13 per cent fall in A&E ophthalmology appointments, whereas before, A&E attendances were constantly rising by up to five per cent a year.

3.6.10 Prab said one of the considerations that had to be taken into account for these services was training. She said in Wolverhampton the primary and secondary eye care partnership had seen a big increase in practitioner training which had resulted in unique training projects for higher competence levels for optometrists. She said in the community, optometrists do not see as much pathology as in hospitals, so they use real patients with real eye conditions for training.

3.6.11 Prab said optometry had adapted to be able to win and manage contracts for extended community eyecare services in Wolverhampton. She said optometry has good levels of governance, transparency with instant statistical analysis using a wellestablished software programme and a ready workforce.

3.6.12 Prab said nationally, the Local Optical Committee Support Unit (LOCSU) had been key to encouraging the development of extended community services and had made progress in the commissioning of these types of schemes in recent years. She said LOCSU’s data shows they have been able to increase such commissioning or intent to commission from 30 per cent to 55 per cent, and are aiming to deliver such schemes to around 80 per cent of CCGs.

3.6.13 Prab said in future, LOCSU is aiming to consolidate smaller primary eye care companies so that they become larger regionalcompanies which match the map for STPs. She said LOCSU will also look to expand the electronic framework to improve the safe sharing of patient data between the primary and secondary sectors to improve communication and feedback. Prab said it is important for optometrists to receive such feedback from hospitals.

3.6.14 Prab said it is also very important for primary eye care companies to adhere to strict clinical governance monitoring procedures, be transparent and accountable and collaborate with CCGs.

3.6.15 Prab suggested the way to improve services across the country is for primary and secondary eye care providers to collaborate with primary eye care companies, CCGs and STPs to reduce demand on the NHS. She said it would involve using community optometrist skills at a national level to provide:

1. An extended community eyecare service model to reduce initial demand on hospital eye services and produce fewer, more refined / appropriate referrals, and
2. An integrated community monitoring model which takes stable / lower risk patients out of hospital eye services and monitors them in the community in line with strict clinical protocols.

3.6.16 Prab said ECLOs are also a very important part of patient care, as patients are often left alone after being told there is no treatment for their vision loss. She said ECLOs have been extremely helpful in counselling patients to cope with their visual impairment, and without them, patients find it extremely difficult to come to terms with their diagnosis.

3.6.17 Prab said we should also look to Scotland where they have changed their GOSmodel, which means patients can be seen in the community without the need for additional services to be commissioned. In Scotland it has resulted in greatly reduced numbers of hospital appointments.

3.6.18 Richard Holmes asked, on the three additional services, how were you successful in getting these commissioned, and how do neighbouring areas compare? How does this shape up compared to other areas and how can this be shared with neighbouring authorities?

3.6.19 Prab said a good relationship with the hospital trust was facilitated by LOCSU who helped them establish a good dialogue and trust between ophthalmology and optometry and a dialogue with CCGs. She said through these meetings the CCG realised the resource potential of the optometrysector, and in terms of neighbouring areas, while the local STP does not mention eye care, they have been engaging with the CCGs in their STP area.

3.6.20 Prab said there was a need to move to national commissioning and a national eye care pathway as local tendering of these contracts can take a very long time and is difficult for CCGs to do. She said having a national pathway will help areas where CCGs are less approachable.

3.6.21 Richard Holmes asked why do we need to go national?

3.6.22 Prab said local tendering processes are laborious and Carolined out on a CCG-by-CCG basis; whereas commissioning on a larger scale would save so much time and effort and could be done, for example, at the STP level.

3.6.23 Richard asked what do you think the Inquiry could recommend to the Government and NHS which would address capacity in eye care services to ensure all patients receive the care they need?

3.6.24 Prab said central commissioning is crucial. In Wolverhampton the opticalsector is being utilised, but other areas do not get heard, we are here and should be used.

3.6.25 Fiona Spencer added that if we do things on a national level we lose the potential for innovation. Fiona said RCOphth recently did a robust presentation to Health Education England[**[[41]](#endnote-42)**], and cited RCOphth who said the number of ophthalmologists is unlikely to increase even though they want it to. Fiona said that national commissioning could result in losing the ability to innovate and create better pathways. Also the service needs more ophthalmologists and some of their local optometrists are the strongest advocates of this. Christina Rennie said she agreed with this viewpoint.

3.7 Christina Rennie, University Hospital Southampton NHS Foundation Trust

3.7.1 Christina Rennie is a Consultant Ophthalmologist at Southampton Eye Unit with a special interest in medical retina and the Clinical Lead for Ophthalmology for the last threeyears, at University Hospital Southampton (UHS) NHS Foundation Trust. The Trust and Southampton City CCG submitted a combined written response to the Inquiry’s Call for Evidence.

3.7.2 Christina explained the Trust provides health services commissioned by Southampton CCG for a population of 285,436people and by West Hampshire CCG for a population of 200,000 people, and there is a wider tertiary referral for many of their specialist services.

3.7.3 Christina detailed some of Southampton’s demographics:

* it has a larger than average student population which Christina said skews CCG funding
* there is a higher than national average population with a non-white British background and English is not their first language
* several areas of deprivation
* an ageing population – a 20 per cent increase in 70-74-year age group between 2014 and 2019, a 15 per cent increase on people over 85 years of age
* issues with/ relating to smoking, obesity, substance misuse, physical inactivity, poor diet and health inequalities
* onethird of people living with long term conditions, high cardiovascular disease and diabetes rates
* Southampton has a higher than national average rate of preventable sight loss, and
* approximately three per cent of the CCG budget is spent on ophthalmology.

3.7.4 Christina outlined the scale of UHS trust’s work. Nationally ophthalmology accounts for eight per cent of outpatient appointments, only orthopaedics is bigger:

* in 2016/17, the trust dealt with 105,000 ophthalmology appointments
* including 21,000 new attendances and 84,000 follow-up appointments (the latter representing a four per cent increase on the previous year) – ophthalmology is an area of chronic disease, hence the large number of follow ups
* each year they have 18,000 paediatric appointments, and
* see 25,000 visits to eye casualty, a number that has not increased.

3.7.5 Christina said UHS’s Ophthalmology Department were consistently meeting the RTT eighteenweek standard until September 2017; but have had some challenges meeting this since then, and referred to the impact of additional West Hampshire CCG activity (provided at Lymington Hospital) and recruitment challenges.

3.7.6 Christina outlined the challenges being faced by UHS’s Ophthalmology Department which she summarised as space, staffing and equipment.

3.7.7 Christina said the eye unit was built over 25years ago for seven consultants; but they now have 21 consultants plus junior doctors, fellows and specialty doctors – nearly 50-doctors in total.

3.7.8 Christina said the challenges were:

* capacity to meet demand from a growth in the population for example due to baby boomers[**[[42]](#endnote-43)**] and the number of people with diabetes
* the availability of new treatments in the last ten-years
* staffing – they are doing well, as an academic unit they have a good reputation and can attract candidates, but this has recently been affected by the impact of the junior doctors’ contract and Brexit, which has made it difficult to recruit
* a lack of theatre space – so they are unable to give more stable job plans and surgical training to attract candidates, and
* they are competing with other hospital specialties for the funding for additional theatre space – Christina said it has taken a crisis in their staffing to get a third theatre moved to the top of the priority list in the hospital.

3.7.9 Christina said the impact of this is they have a backlog, especially within glaucoma and medical retina and means patients are at risk of losing sight.

3.7.10 Christina said the CCG’s response to the challenges had been to establish the following:

1. A MECS – Christina said optical practices in and around Southampton have reduced pressure on GPs and eye casualty. She said the CCG had been hugely supportive of this initiative, it has paid for optometrists to work in the eye unit to develop pathways, there is shared learning and optometrists attend Morbidity and Mortality meetings[**[[43]](#endnote-44)**]. MECS had been proactive in directing patients away from hospitals; but is only available to patients in Southampton, and not those in West Hampshire. Christina said it needs joined up commissioning between West Hampshire and Southampton City.
2. The Solent Medical Service – providing a community glaucoma and primary care ophthalmology service run by GPs with a special interest, and
3. An Independent Sector Treatment Centre (ISTC) run by the company Care UK – Christina said there had been a mixed effect for UHS as the ISTC had been able to ‘cream off easy cases’, and UHS was left with the difficult cases or patients.

3.7.11 Christina said ophthalmology was competing as a priority with other specialties and areas of health and social care, and gave the example of the challenges they are facing funding an ECLO. She said people see the benefit of investing in eye health; but not at the cost of losing something else. Christina said there is a constant battle to keep eye health prevention, detection and management, on the radar of the right people in terms of investment and influence.

3.7.12 Next, Christina set out how UHS had addressed the challenges (see 3.7.8), which she summarised as pathway refinement, a virtual service, workforce redesign and a ‘hospital without walls’.

1. Creating a very lean pathway for AMDpatients – the hospital has been working with Bayer on patient flow. They set out to ensure staff know how to learn to manage clinics, so that staff do not have to find a consultant to discuss every case as they know the pathway. Clinical trials were undertaken on this, with patients receiving two reviews in year one and two monthly injections. Christina said audits showed one-year outcomes matched clinical trials, and they have been able to reduce the number of appointments AMD patients have, while achieving the same clinical outcomes.
2. Christina said they currently have lots of referrals for AMD as people know about it – some people do not need treatment and could manage in the community.
3. With ‘hospitals without walls’ they have set up a virtual clinic or mobile unit which they use to deliver care for medical retina and administer anti-VGEF injections to AMDpatients, and they plan to expand this for glaucoma.
4. On workforce redesign:
* Christina said clinics are not training enough ophthalmologists because the eye department did not have enough junior doctors, so UHS set up an internal CESRtraining[**[[44]](#endnote-45)**] programme to get doctors onto the Specialist Register, and they are treated the same as their deanery trainees, and
* Training allied staff – nurses, orthoptists and optometrists – to undertake injections and reviews in medical retina, AMD and glaucoma clinics and giving them an extended role in eye casualty. Christina said UHS want to expand this, but it needs national training guidance.
1. Using other sites such as a small hospital at Lymington has given UHS more theatre space, which Christina said together with raising the standard of equipment, often through charitable funding, has enabled it to deliver more.
2. Partnering with charities – UHS are about to run a low-vision clinic within their premises.
3. Post-operative follow-up into the community.
4. Christina said GIRFT praised UHS for their very efficient use of space. UHS run theatre evening lists twonights a week and Saturdaylists most weekends, and clinics on alternate Saturdays as part of their move to sixday working, and
5. Hiring theatre space in the private sector and running a training list at CareUK.

3.7.13 Christina summarised the key challenges as being: physical space, theatre and cubicles; hiring staff, doctors, nursing, allied; and equipment, and they need to allow them to expand off site working and virtual clinics.

3.7.14 Christina’s recommendations were:

1. Capital funding – for more facilities, space and beds
2. Support RCOphth’smeasures:
* introduce key performance indicators to drive up quality
* there are competencies for allied staff but there is no national training programme which is needed, and
* share best practice such as the GIRFTProgramme which is looking at reducing clinical variation between hospitals which must be listened to.
1. Christina said they have been swamped by workload but they have had to problem-solve to introduce new ideas. She said you need proper projectmanagement support to put things into practice and manage effectively and funding to implement changes rather than firefight.

3.7.15 Richard Holmes asked Christina do you agree with Fiona that the priority is more about sharing good practice than national targets, which it has been suggested may inhibit innovation?

3.7.16 Christina said yes and GIRFT will be very helpful in making that happen. She said the challenge is making ideas happen and to ensure people have the headspace to implement change. She said there is also an issue of management and said she has had a new manager every year for the last eight years, and there needs to be better project management.

3.7.17 Richard asked are CCGs and managers aware of increasing numbers of patients coming into eye clinics? Or are experts such as Christina having to make the CCG and managers aware?

3.7.18 Christina said at UHS the CCG and managers are aware of increasing demand. Some are very engaged but not so much in other areas. She said there is a need to get the right people behind eye care. In Southampton she said the STPplan has only one line on ophthalmology which just refers to moving services into the community, not the hospital eye service.

3.7.19 Fiona Spencer raised concerns about AQPs because she said they can destabilise the provision and continuity of services.

3.7.20 Prab Bopari said in Wolverhampton the STP has not prioritised ophthalmology because they have focussed on tackling issues in A&E and cancer services, but they do have outpatient services in their scope. So, she has been engaging with them from this perspective about eye care services. She said outpatient management are helpful and see that optometrists can help reduce pressure on hospitals.

3.7.21 Richard asked what do you think the Inquiry could recommend to the Government and NHS which would address capacity in eye care services to ensure all patients receive the care they need?

3.7.22 Christina said she would recommend capital funding to upgrade facilities and said measures that are already in place are necessary just to cope with present demand, but they also need to meet future demand. She said they need more space and to recruit more staff and probably to co-locate services.

4. Endnotes

1. **.** Age-related macular degeneration (AMD) affects a tiny part of the retina at the back of the eye, called the macula. A person develops wet AMD when the cells of the macula stop working correctly and their body starts growing new blood vessels to fix the problem. As these blood vessels grow in the wrong place, they cause swelling and bleeding underneath the macula – which is why it is called ‘wet’ AMD. It causes more damage to the macula and eventually leads to scarring. Both the new blood vessels and the scarring damage the central vision and may lead to a blank patch in the centre of their sight. Wet AMD can develop very quickly, causing serious changes to your central vision in a short period of time, over days or weeks (“Understanding AMD”, RNIB and RCOphth (2016)). [↑](#endnote-ref-2)
2. **.** “Guide to essential care for wet age-related macular degeneration (wet AMD)”, The Macular Society (2015). [↑](#endnote-ref-3)
3. **.** The treatment available on the NHS for wet AMD is a group of medications called anti‑vascular endothelial growth factor (anti‑VEGF) drugs. As new blood vessels form in the eye, the body produces a chemical which encourages further new blood vessel growth. Anti-VEGF drugs interfere with this chemical and stop the vessels from growing, preventing further damage to your sight. The medication has to be injected into the vitreous, which is a gel-like substance inside the eye (“Understanding AMD”, RNIB and RCOphth (2016)). [↑](#endnote-ref-4)
4. **.** Bevacizumab or Avastin (its brand name) has not to date been authorised by NICE for the treatment of wet AMD. [↑](#endnote-ref-5)
5. **.** Aflibercept or Eylea (its brand name) is one of two types of anti-VEGF medication currently available on the NHS for the treatment of wet AMD. To start with, patients will have a monthly injection of Eylea for three consecutive months. There is no need for monitoring between injections. Depending on the outcome of treatment, a patient may have further injections once every two months. After 12months, the intervals between injections may be extended depending on how well the medication is working. In this case, the doctor treating the patient will determine a monitoring schedule ([www.nhs.uk/conditions/macular-degeneration/treatment/](file:///C%3A/Users/AFRENCH/Documents/www.nhs.uk/conditions/macular-degeneration/treatment/)). [↑](#endnote-ref-6)
6. **.** The Patient Advice and Liaison Service offer confidential advice, support and information on health-related matters, and provide a point of contact for patients, their families and their carers. [↑](#endnote-ref-7)
7. **.** Ranibizumab or Lucentis (its brand name) is the other anti-VEGF medication currently available on the NHS for the treatment of wet AMD. To start with, patients will have a monthly injection of Lucentis for three consecutive months. The patient’s visual acuity will then be monitored during a maintenance phase. If their vision deteriorates during the maintenance phase, and it is thought to be caused by further fluid leakage, they may be given another injection of Lucentis. Monitoring will continue, and the patient will have injections as necessary, with at least one month between injections. Treatment with Lucentis will be stopped if the condition does not show signs of improvement or continues to get worse ([www.nhs.uk/conditions/macular-degeneration/treatment/](file:///C%3A/Users/AFRENCH/Documents/www.nhs.uk/conditions/macular-degeneration/treatment/)). [↑](#endnote-ref-8)
8. **.** Thyroid eye disease is an eye condition that causes the muscles and soft tissues in and around the eye socket to swell. It usually happens when a person has a problem with their thyroid gland (“Eye Condition Fact Sheet – Thyroid Eye Disease”, RNIB (2016)). [↑](#endnote-ref-9)
9. **.** Glaucoma is an eye condition where the optic nerve is damaged by the pressure of the fluid inside the eye. This may be because eye pressure is higher than normal, or because of a weakness to the optic nerve (“Understanding Glaucoma”, RNIB and RCOphth (2016)). [↑](#endnote-ref-10)
10. **.** A cataract is a clouding of the lens in the eye which sits just behind the iris, the coloured part of the eye. Normally the lens is clear and helps to focus the light entering the eye. Developing cataracts will cause a person’s sight to become cloudy and misty (“Understanding Cataracts”, RNIB and RCOphth (2016)).

 [↑](#endnote-ref-11)
11. **.** The Care Quality Commission is an executive non-departmental public body of the Department of Health and Social Care of the, which is the independent regulator of health and social care in England. It **registers** care providers; **monitors, inspects and rates** services; takes **action to protect people** who use services; and publishes its views on major quality issues in health and social care (www.cqc.org.uk/). [↑](#endnote-ref-12)
12. **.** Chronic obstructive pulmonary disease or COPD is the name for a group of lung conditions that cause breathing difficulties. It includes: emphysema, damage to the air sacs in the lungs; and chronic bronchitis, long-term inflammation of the airways. [↑](#endnote-ref-13)
13. **.** Eye Clinic Liaison Officers (ECLOs) (also known as sight loss advisers or Vision support service officers), work closely with medical and nursing staff in the eye clinic, and the sensory team in social services. They provide people recently diagnosed with an eye condition with the practical and emotional support which they need to understand their diagnosis, deal with their sight loss and maintain their independence ([www.rnib.org.uk/ecloinformation](http://www.rnib.org.uk/ecloinformation)). [↑](#endnote-ref-14)
14. **.** From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss ([www.england.nhs.uk/ourwork/accessibleinfo/](file:///C%3A/Users/AFRENCH/Documents/www.england.nhs.uk/ourwork/accessibleinfo/)). [↑](#endnote-ref-15)
15. **.** When diabetes affects the network of blood vessels supplying the retina at the back of the eye, it is called diabetic retinopathy. Diabetes can cause the blood vessels to become blocked, to leak or to grow incorrectly. If there is a leakage of fluid from the blood vessels near the macula, this fluid can build up and cause macular swelling. This is called diabetic macular oedema and it can cause vision to be blurred and distorted, as well as making colours appear washed out (“Understanding conditions related to Diabetes”, RNIB and RCOphth (2016)). [↑](#endnote-ref-16)
16. **.** Type1 diabetes is an auto-immune condition, which means the immune system attacks healthy body tissue by mistake. In this case, it attacks the cells in the pancreas. The damaged pancreas is then unable to produce insulin. So, glucose cannot be moved out of the bloodstream and into the cells. Diabetes cannot be cured. Treatment aims to keep the patient’s blood glucose levels as normal as possible and control the symptoms, to prevent health problems developing later in life. As the body cannot produce insulin, the patient will need regular insulin injections to keep their glucose levels normal (www.nhs.uk/conditions/type-1-diabetes/). [↑](#endnote-ref-17)
17. **.** An OCT or optical coherence tomography scan uses special rays of light to scan a patient’s retina and produce an image of it. It can provide detailed information about the macula. For example, it will tell your ophthalmologist whether your macula is thickened or abnormal, and whether any fluid has leaked into the retina (www.nhs.uk/conditions/macular-degeneration/diagnosis/). [↑](#endnote-ref-18)
18. **.** Receiving a CVI enables a person to register they are blind or partially sighted with their local authority, entitling them to an assessment of needs and access to services. [↑](#endnote-ref-19)
19. **.** NICE, the National Institute for Health and Care Excellence is an executive non-departmental public body of the Department of Health and Social Care, which publishes guidelines on the use of health technologies within the NHS (such as the use of new and existing medicines, treatments and procedures) and clinical practice (guidance on the appropriate treatment and care of people with specific diseases and conditions) (www.nice.org.uk/). [↑](#endnote-ref-20)
20. **.** Primary Care Trusts were part of the NHS in England from 2001 to 2013. They were largely administrative bodies, responsible for commissioning primary, community and secondary health services from providers. [↑](#endnote-ref-21)
21. **.** Health and wellbeing boards were established under the Health and Social Care Act 2012 to act as a forum in which key leaders from the local health and care system could work together to improve the health and wellbeing of their local population. They are a formal committee of the local authority charged with promoting greater integration and partnership between bodies from the NHS, public health and local government. [↑](#endnote-ref-22)
22. **.** Joint Strategic Needs Assessments are assessments of the current and future health and social care needs of the local community. These are needs that could be met by the local authority, CCGs, or the NHS Commissioning Board. They are produced by health and wellbeing boards and are unique to each local area. [↑](#endnote-ref-23)
23. **.** Local Optical Committees are statutory bodies established within the NHS to represent the interests of community optometrists and opticians. There are 78 Local Optical Committees in England. They are supported by the Local Optical Committee Support Unit which provides a link to the national bodies the Association of British Dispensing Opticians, the Association of Optometrists and the Federation of (Ophthalmic and Dispensing) Opticians. [↑](#endnote-ref-24)
24. **.** The Diploma in Glaucoma is designed to prepare optometrists to participate in community or hospital-based schemes for the management of patients with established glaucoma deemed suitable for management by optometrists (www.college-optometrists.org/). [↑](#endnote-ref-25)
25. **.** The PHOF for England sets out the Government’s priorities for public health. It includes an indicator to highlight the rate of preventable sight loss in the population which is based on the total number of new CVIs issued per 100,000 people. It also reports on certificates issued to people, in certain age groups, as a result of AMD, glaucoma and diabetic eye disease [(www.gov.uk/government/collections/public-health-outcomes-framework](file:///C%3A/Users/AFRENCH/Documents/%28www.gov.uk/government/collections/public-health-outcomes-framework)). [↑](#endnote-ref-26)
26. **.** **Amblyopia or a "lazy eye" is a childhood condition where the vision does not develop properly.** It happens because one or both eyes are unable to build a strong link to the brain. It usually only affects one eye and means that the child can see less clearly out of the affected eye and relies more on the "good" eye. It is usually a sign of another condition that could lead to a lazy eye, such as: **a squint,** **refractive errors,** or **childhood cataracts** (www.nhs.uk/conditions/Lazy-eye/). [↑](#endnote-ref-27)
27. **.** The POPPI or Projecting Older People Population Information and the PANSI or Projecting Adult Needs and Service Information systems are developed by the Institute of Public Care. They are for use by local authority planners and commissioners of social care provision in England and designed to help explore the possible impact that demography and certain conditions may have respectively on population groups aged 65 and over, and aged 18 to 64 ([www.poppi.org.uk/](file:///C%3A/Users/AFRENCH/Documents/www.poppi.org.uk/); www.pansi.org.uk/). [↑](#endnote-ref-28)
28. **.** There are 44 Sustainability Transformation Partnerships across England which have been developed by local NHS organisations and councils to draw up plans to improve NHS services and population health in their geographical area. Their aim is to help deliver better health, transformed quality of care delivery and sustainable finances in line with the NHS “Five Year Forward View” (2014) ([www.england.nhs.uk/](file:///C%3A/Users/AFRENCH/Documents/www.england.nhs.uk/)). [↑](#endnote-ref-29)
29. **.** Hospital Episode Statistics data is collected during a patient's time at hospital and submitted to allow hospitals to be paid for the care they deliver. It contains details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England ([content.digital.nhs.uk/hes](http://content.digital.nhs.uk/hes)). [↑](#endnote-ref-30)
30. **.** The Friends and Family Test is used in most NHS-funded services in England. It asks people if they would recommend the services they have used and offers a range of responses. NHS England state that when combined with supplementary follow-up questions, the test provides a mechanism to highlight both good and poor patient experience, which can help transform NHS services and support patient choice. [↑](#endnote-ref-31)
31. **.** Foot B., MacEwen C. (2017). “Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome”. Eye, 31: 771–775. [↑](#endnote-ref-32)
32. **.** NHS England’s website states: “In England, under the NHS Constitution, patients ‘have the right to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer a range of suitable alternative providers if this is not possible’. The NHS Constitution sets out that patients should wait no longer than 18 weeks from GP referral to treatment” (<https://www.england.nhs.uk/resources/rtt/>). [↑](#endnote-ref-33)
33. **.** AQP is a contractual system within the NHS under which any provider assessed as meeting rigorous quality requirements who can deliver services to NHS prices under the NHS Standard Contract is able to deliver the service (www.england.nhs.uk/) [↑](#endnote-ref-34)
34. **.** The RCOphth commissioned “The Way Forward” (2017) to identify current methods of working and schemes devised by ophthalmology departments in the UK to help meet the increasing demand in ophthalmic services. The information aims to offer a helpful resource for ophthalmologists who are seeking to develop their services to meet capacity needs ([www.rcophth.ac.uk/standards-publications-research/the-way-forward/](https://www.rcophth.ac.uk/standards-publications-research/the-way-forward/)) [↑](#endnote-ref-35)
35. **.** **Diabetic retinopathy is a complication of diabetes, caused by high blood sugar levels damaging the back of the eye (retina). It can cause blindness if left undiagnosed and untreated (www.nhs.uk/conditions/Diabetic-retinopathy/).** [↑](#endnote-ref-36)
36. **.** A Yag capsulotomy is a special laser treatment used to improve a patient’s vision after cataract surgery. During a cataract operation, the natural lens inside the eye that had become cloudy is removed. A new plastic lens is put inside the lens membrane in the eye. In a small number of patients, the capsule thickens after surgery and becomes cloudy. This interferes with the light reaching the back of the eye. When this happens, the patient’s sight becomes misty, and they may get glare in bright light or from lights at night-time. In a Yag laser capsulotomy the doctor uses a special lens to apply a laser beam to the capsule. This creates a small hole in the centre of the capsule, which lets light through (Guys and St Thomas’ NHS Foundation Trust). [↑](#endnote-ref-37)
37. **.** Myopic CNV occurs in people who are very short-sighted. When someone is highly short-sighted, the retina at the back of the eye is stretched due to the increased size of the eye associated with short-sightedness. This stretching can make the retina thinner and prone to splitting. When this occurs, blood vessels from the choroid (the layer of the eye behind the retina) can grow into the retinal space. These new vessels (neovascularisation) leak blood and fluid, which can prevent the retina from working properly. Severe damage leads to severe permanent loss of central vision (“Patient information – Anti-VEGF intravitreal injection treatment”,Moorfields Eye Hospital NHS Foundation Trust (2012), www.moorfields.nhs.uk). [↑](#endnote-ref-38)
38. **.** “Taking Control, Shaping our Future – Cornwall and the Isles of Scilly Health and Social Care Plan 2016-21” ([www.shapingourfuture.info/](http://www.shapingourfuture.info/)). [↑](#endnote-ref-39)
39. **.** Asymptomatic means a patient is a carrier for a disease or infection but experiences no symptoms. [↑](#endnote-ref-40)
40. **.** In England, the General Ophthalmic Mandatory Services (GOS) model is used to commission NHS primary eye care services. There are two types of GOS contract: (1) Mandatory services contract for fixed premises and (2) Additional contract for mobile services. Service providers contracted to provide the service are optometrists or ophthalmic medical practitioners. The GOS-contract says they must do a sight test to check whether a person’s vision needs correcting, e.g. with glasses; and there is an additional duty to examine their eyes for any injury, disease or abnormality, and refer them to hospital eye services, if appropriate. In England people are eligible for GOS-sight tests if aged under 16; aged 16-18 and in full-time education; aged 60 or over; registered blind or partially sighted; diagnosed with diabetes or glaucoma; aged 40 or over with a first degree relative with glaucoma; or if they receive a specified means tested social benefit (“General Ophthalmic Mandatory Services Model Contract”, Department of Health (2010)). [↑](#endnote-ref-41)
41. **.** Health Education England is an arm’s length body of the Department of Health, which provides national leadership and coordination for education and training within the health and public health workforce within England (www.hee.nhs.uk/). [↑](#endnote-ref-42)
42. **.** ‘Baby boomers’ refers to people born following the Second World War between 1946 and 1964 when there was a very high increase in the birth rate, meaning people who as of 2018 are aged between their early fifties and early seventies. [↑](#endnote-ref-43)
43. **.** Morbidity and Mortality meetings: “focus on finding ways to support staff to be open with each other and share problems that they encounter. The aim is to improve patient care by developing a culture of awareness of quality and encouraging front line staff to identify harm, report problems and share lessons to prevent recurrence.” (“Morbidity and mortality meetings to improve patient care”, General Medical Council). [↑](#endnote-ref-44)
44. **.** The CESR or Certificate of Eligibility for Specialist Registration is a route to entry onto the Specialist Register for those doctors who have not followed an approved training programme. **The Specialist Register** is a list of doctors who are legally entitled to take up honorary, substantive or fixed term consultant posts in the NHS and is maintained by the GMC. Hospital doctors are included on the Specialist Register after they have been awarded either a Certificate of Completion of Training (CCT) or a Certification of Eligibility for Specialist Registration (CESR) (www.bma.org.uk). [↑](#endnote-ref-45)