

Saving money, losing sight.

RNIB campaign report executive summary

November 2013

Foreword

Sight is precious. Sight is the sense we most fear losing. However, today, patients are going blind unnecessarily because of capacity problems in eye clinics across England. This is the shocking reality as eye clinics are simply too busy to keep up with demand.

Patients are of course incredibly grateful to ophthalmology staff who work long hours, under intense pressure, even putting free time to one side in order to run extra clinics. Many patients describe the service they receive as 'marvellous' and 'first class'. However, they also express concerns about aspects of their care including cancelled and delayed appointments, over-subscribed clinics, long waits to see a professional at each appointment and rushed consultations.

These problems are frequently caused by lack of capacity in eye clinics - where staff are being asked to do ever more with the same resources. Staff describe their working conditions as "chaotic" and "running from one crisis to another." Despite raising alarm bells and asking for additional support, their requests are not being heard. Hospital managers are all too often ignoring the capacity crisis, putting patients' sight at risk and their staff on course for burnout.

This situation is made worse by the fact that commissioners, who plan and fund healthcare services locally, are not always working with accurate information on the eye care needs of their local populations. Department of Health guidance states that commissioners should refer to local authority Joint Strategic Needs Assessments (which analyse the health and wellbeing needs of the local community) when making decisions. However, less than half of these assessments contain information on eye health. This inevitably means eye care service planning is a hit or miss affair. Whether you lose or keep your sight depends simply upon where you live - a terrible "postcode lottery."

This situation cannot continue - urgent action is needed to stop people losing their sight unnecessarily.

Lesley-Anne Alexander CBE
RNIB Chief Executive

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Clara Eaglen, Policy and Campaigns Manager, RNIB

About RNIB

Royal National Institute of Blind People (RNIB) is the leading charity in the UK offering information, support and advice to almost two million people with sight loss.

We are a membership organisation with over 10,000 members who are blind, partially sighted or the friends and family of people with sight loss.

Our three main priorities are set out by our five year strategy (2009-2014):

- stopping people losing their sight unnecessarily
- supporting independent living
- creating an inclusive society.

As a campaigning organisation, we fight for the rights of blind and partially sighted people across the UK and push for better access to diagnosis and treatment to prevent avoidable sight loss.

Executive summary

Introduction

Losing sight can have an enormous emotional and financial toll. Some patients report feeling depressed, anxious and emotionally distraught.

Without sight, people are at risk of losing their employment and their ability to travel independently as well as having to rely on carers to undertake day to day tasks. They are also at higher risk of experiencing falls and accidents which require further NHS health and social care services.

Over the last decade, many new treatments have been developed, saving the sight of thousands of people who would previously have gone blind. This is an enormous and welcome step forward. However, despite these advances, a worrying development is now placing patients' sight at risk - a looming capacity crisis in ophthalmology.

Patients are incredibly grateful to the hard working staff in eye clinics but do have significant concerns about aspects of their care such as cancelled and delayed appointments, long waits to see a professional at each appointment and rushed consultations. Patients we have spoken to realise that staff are doing everything they can to save their sight but are under considerable pressure. For example, we hear that:

“The eye hospital clinics are total chaos! The appointment time bears no relationship to when you will be seen. I find it so hard to sit for hours not knowing what is happening. The staff are nice but totally overrun.”

“I knew delays would lead to permanent damage that could never be reversed - I started to think I would never gain access to what I needed to save my sight before I lost it forever.”

“When the specialist says he wants to see you in three months, you should see him in that timeframe, instead of having to wait for seven months during which time your condition has worsened.”

“I attend the eye clinic every three months. I have laser, it's like a cattle market and I feel I am just another number.”

Anecdotal evidence suggests that lack of capacity in eye clinics is to blame for the delays to diagnosis and treatment, and that this could be putting the

sight of tens of thousands of people at risk. To investigate, we undertook research to examine ophthalmology staff views on capacity. Additional research was conducted to gather intelligence on the mechanisms used by local authorities and commissioners to assess, plan and deliver eye care services for local populations.

Methodology

In summer 2013, RNIB carried out a survey of staff in eye clinics across England. We asked about current and future capacity, the impact of insufficient capacity on patient care and possible solutions. By September 2013, 172 responses were received from a range of eye health professionals including 91 ophthalmologists and 59 ophthalmic nurses.

As local authorities and clinical commissioning groups (CCGs) work together to assess the health needs of their local populations; RNIB decided to undertake additional research to supplement the findings of the staff survey and examine the commissioning process as a whole. To do this, online research was conducted to assess which local authority Joint Strategic Needs Assessments (JSNAs) include information and data on eye care and sight loss. JSNAs are important as CCGs must refer to them when making commissioning decisions.

Finally, a Freedom of Information request was sent to all CCGs across England seeking information on the evidence they use to commission eye care services.

Our findings show that:

So what did our research reveal? Is capacity a major problem in ophthalmology and is it having a detrimental impact on patient care? The simple and unfortunate answer is yes. Our findings show that:

- **Patients are going blind due to sizeable capacity problems in ophthalmology clinics across England:**

37 per cent of respondents said that patients are "sometimes" losing their sight unnecessarily due to delayed treatment and monitoring caused by capacity problems. A further four per cent of respondents said this is happening "often". These statistics are shameful as nobody should lose sight from a treatable condition simply because their eye clinic is too busy to treat them in a clinically appropriate timescale.

In relation to these findings, Nicola Wainwright, a partner at leading clinical negligence law firm Leigh Day, told us: "As clinical negligence specialists, we have acted for clients whose long term vision has been permanently affected when, for example, their diagnosis, treatment or follow-up has been delayed. In such cases, lack of capacity in the eye clinic seems to have contributed to fundamental breaches of care, giving rise to claims in clinical negligence."

In addition to sight loss, lack of capacity gives rise to other negative implications for patient care and by far the biggest problem (according to 82 per cent of respondents) is rescheduled and cancelled appointments. Other issues include long waits to see a professional at each appointment, which can be two to three hours, and rushed appointments, leaving little time for the patient to discuss their eye condition and its treatment with their professional. This leads to misunderstandings and considerable amounts of stress for both the patient and professional. It also hampers the patient's ability to make an informed choice about their care.

- **The capacity crisis in ophthalmology is countrywide with clinics under extreme pressure to meet demand:**

Staff in all regions of England responded to the survey and over 80 per cent of respondents said their eye department has insufficient capacity to meet current demand. Over half said the problems are so significant that they have to undertake extra clinics in the evenings and at weekends to keep up with demand. Many departments report a huge backlog of patients and chronic understaffing. It is clear that eye clinics are in fire fighting mode and that the relentless schedule, resulting in long working hours, is putting staff at serious risk of burnout.

The situation gets worse when respondents were asked about capacity in the longer term, with 94 per cent reporting that future capacity will not meet rising demand.

Lack of capacity is of course a complex issue and many factors contribute to the problem. However, our research has uncovered four reasons which seem to be the main drivers:

- 1. A significant increase in demand for services across a broader range of conditions:**

The majority of survey respondents agreed that the ageing population (87 per cent) and availability of new treatments (88 per cent) have led to a rapid increase in demand for services.

A new type of treatment, known as anti-vascular endothelial growth factor (anti-VEGF), has resulted in greater numbers of patients needing regular monitoring and treatment. This development is a warmly welcomed and has saved the sight of many patients who would otherwise have gone blind. It has also placed sizable strain on eye departments. Staff report being “overwhelmed” by anti-VEGF clinic appointments and many (70 per cent of respondents) say this has impacted upon other eye care services, as managers re-direct funding and staff resources into these clinics. Some respondents warn that the focus on conditions that can be treated with anti-VEGFs mean that people with other chronic eye conditions are going blind while they wait for an appointment. This is despite the fact that potential numbers of patients were predicted well in advance.

Potential treatments for dry AMD – currently an untreatable disease – are also likely to be available within the next five to ten years. This will be a significant and hugely welcomed development but will place additional strain on eye clinics, with even greater numbers of patients needing regular monitoring and treatment. This is why it is so important to manage capacity sooner rather than waiting for the crisis to get worse.

2. No clear strategy for coping with current and future demand:

Just over half (52 per cent) of survey respondents said their department reviews current need to ensure service provision meets demand. This number drops to 44 per cent when asked if they also consider future need. In the case of departments that do not plan, respondents suggest that heavy workload prevents them having time to review resourcing needs.

When eye clinics do review demand and produce business cases seeking extra resources, their requests are often dismissed by hospital trust management, usually due to financial constraints. Survey respondents report that ophthalmology is only seen as a minor issue by Hospital Trust Boards and is rarely given the priority it deserves. Many respondents state that management only address problems when departments are at breaking point and that this often involves short term solutions such as recruiting expensive locums to alleviate immediate staff shortages.

3. A lack of local planning of eye health and sight loss services:

Although preventing unnecessary sight loss has been prioritised in the Government's Public Health Outcomes Framework, our research reveals a lack of eye health population planning in many areas of the country. Only 40 per cent of all Joint Strategic Needs Assessments (JSNAs) in England contain information on sight loss and eye health. Some regions are worse than others, for example, 93 per cent of JSNAs in the West Midlands and

82 per cent in the North West have little or no information on sight loss. This is problematic as local authorities have been asked to demonstrate improvements in public health outcomes against the issues listed within their JSNA.

4. An inconsistent approach to commissioning eye care services:

There is no consistent approach to commissioning eye care services across England. Department of Health guidance states that CCGs must refer to their local JSNAs and local authority public health advice when making decisions about commissioning services. However, our Freedom of Information (FOI) survey reveals that only 64 per cent actually do. In some cases, CCGs are using JSNAs that do not contain information on eye health and sight loss, which is the case with NHS Birmingham South and Central CCG and NHS Knowsley CCG.

Findings also show that CCGs are making commissioning decisions based on very different levels of evidence. Some, such as NHS South Devon and Torbay CCG, are to be applauded for undertaking in-depth, independent evaluations of the eye health needs of their local populations, while others rely solely on JSNAs and public health advice from their local authorities. Between these two extremes, CCGs are referring to an array of sources to facilitate their commissioning decisions and these differ both in quality and quantity. Such inconsistent use of evidence can only lead to a decision making postcode lottery and be detrimental to patient care.

Our findings also reveal that a quarter of commissioning groups have no lead for eye care. Poor dialogue between CCGs and ophthalmology specialists is reported to be hampering commissioners' ability to plan and deliver high quality eye care.

Recommendations

These shocking results should act as a wake-up call to the Government, NHS England, commissioners and hospital trusts alike. Urgent action is clearly needed to prevent people losing their sight needlessly and ensure effective and efficient eye care services are in place to meet rising demand. To do this, RNIB calls for action against the following six recommendations:

1. NHS England must undertake an urgent inquiry into the quality of care in ophthalmology

Recommendation for NHS England

RNIB calls on the Medical Director of NHS England to undertake an independent inquiry into the quality of patient care in ophthalmology. This must be done rapidly and produce viable recommendations that put an end to unnecessary sight loss.

It is profoundly wrong that people are going blind unnecessarily simply because ophthalmology clinics are unable to meet rising demand within existing budgets. There should not be a price on sight. Giving evidence to the Public Accounts Committee earlier this year, Sir Bruce Keogh acknowledged that commissioners ration cataract surgery without using the best available evidence. RNIB is now calling on Sir Bruce to go a step further and use the findings of this report as the basis of an independent investigation into the standards of care in ophthalmology. Patients deserve high quality care and NHS staff deserve access to sufficient resources in order to deliver those standards.

2. National leadership is put in place to address unacceptable variation in eye care provision

Recommendation for Health Ministers and NHS England

NHS England must create a National Clinical Director (NCD) for eye care. This will ensure clinical leadership is at the heart of NHS decision making and ready to meet the challenges that lie ahead as the population ages and the prevalence of eye conditions increases.

Eye health was the most obvious gap in the list of 24 NCD appointments announced in December 2012, which covered almost all of the other major areas of NHS expenditure. Not only would an NCD be "inside the tent" arguing the case for greater prioritisation of eye health, they would also play a key role in co-ordinating services, delivering system re-design and making optimum use of scarce resources.

3. Hospital managers and staff must work together to identify and address capacity problems in their eye clinics

Recommendation for hospital managers and ophthalmology staff

Hospital trust managers and ophthalmology staff (at all levels) must urgently meet to discuss capacity issues in their eye clinic. Problems should be rapidly identified alongside the resourcing requirements needed to address any issues. These meetings must continue on a regular basis to keep the capacity situation under review. Suggested questions to assist with strategic planning can be found in appendix four of this report.

4. CCGs must properly assess and adequately fund eye clinics so they can meet rising demand for services

Recommendation for NHS England, CCGs and CCG Accountable Officers

CCGs should undertake an independent assessment of the eye care needs of their local population to supplement the public health advice they receive from local authorities and their JSNA. There are good practice examples of this from the UKVS project "Commissioning for Effectiveness and Efficiency" covering Torbay, Bedfordshire and Gateshead. Commissioners must work with hospital managers and ophthalmology staff to ensure they fully understand patients' needs and the resourcing requirements needed by ophthalmology departments.

Once need is established, it is vital that commissioners provide proper funding to eye clinics to ensure that no patient loses their sight unnecessarily. Introducing innovation and efficiencies into service provision may help ease the strain but will not solve the capacity problems unless coupled with extra investment. Appropriate levels of funding will enable ophthalmology departments to recruit sufficient staff with the right skill mix, purchase appropriate equipment, acquire new clinic space and, most importantly, offer diagnosis and treatment in clinically appropriate timeframes

NHS England should include a clause in the standard NHS contract requiring ophthalmology providers to use clinical management systems. This will make it easy to retrieve eye care data relating to patient outcomes and clinic activity, and help CCGs monitor and understand the service they are commissioning and the resource requirements needed to run effective and efficient ophthalmology services.

5. National Institute for Health and Care Excellence (NICE) must prioritise the production of its eye health clinical guidelines and Quality Standards

Recommendation for the Government, NHS England and NICE

The Government, NHS England and NICE must bring forward the development of the clinical guideline and Quality Standards (QS) for cataract and age-related macular degeneration. RNIB understands that development of these, along with the refresh of the Glaucoma guideline and Quality Standard, will not commence before 2018. This is simply unacceptable as there is widespread variation in eye care services and

major delays in accessing timely diagnosis and treatment. Five years is too long to wait for a problem that needs resolving now.

There is also a clear gap in the development of guidance and a Quality Standard for diabetic eye conditions. These conditions are the leading cause of blindness among the working age population and a standard on diabetic retinopathy/maculopathy must be added to the NICE library for development.

RNIB is working with the Royal College of Ophthalmologists on the production of cataract and glaucoma commissioning guidance (using a NICE accredited process); however, these will not replace official NICE guidance. NICE Quality Standards help commissioners plan and deliver high quality services and eradicate unacceptable variation. They also assist providers in monitoring service improvements and explain to patients what to expect so they can act if the system fails them.

6. Eye Clinic Liaison Officers (ECLOs) must be an integral part of the patient pathway

Recommendation for commissioners, hospital trust managers and providers

Survey respondents unanimously agree that capacity pressures mean patients have less time to spend with professionals at each appointment. Consultation times are constantly being whittled away by the pressure to see more patients in the same amount of time.

ECLOs provide an obvious solution to this problem, as they work closely with medical and nursing staff in the eye clinic and have the time to dedicate to patients following their consultation. They help patients understand their condition, its treatment and connect them to further practical and emotional support, helping to integrate health and social care services. Patients regularly tell RNIB that they do not want to be given leaflets as a substitute for high quality communication and face to face time with a professional. At present, 56 per cent of eye clinics in England do not have ECLO support in place, which is why RNIB calls for ECLOs to be made an integral part of the eye care patient pathway and ophthalmology team.

In their own words

Mark Jonson, 42, East of England

Mark lives in the East of England and was diagnosed with diabetic macular oedema (DMO) in late 2012. The condition resulted in his sight becoming blurry, making it hard to watch TV or read. As a diabetic, he needs to count the carbohydrates he eats and with DMO this was almost impossible.

Concerned for his sight and the effect losing it might have on his job and life, he was relieved to discover that a new sight saving treatment was available under his private medical cover. Mark started treatment in January 2013 but after three months his insurer refused to pay for further treatment as it had been approved for use on the NHS.

This good news meant that in July 2013, Mark had his first treatment as an NHS patient. However, the good news did not last long as the doctor said the treatment was no longer available because the hospital was not ready to provide it. Despite having a legal right to this treatment, Mark was still waiting for a follow-up appointment in October 2013.

During this time Mark's sight deteriorated to the point where he could no longer drive, which restricted the business meetings he could attend and began to affect his personal life - many of Mark's friends and family live far away so he has to travel to visit them. Commenting on this period, Mark said: "I felt very worried, if not terrified, as I really thought I was going to lose my sight. I am relatively young and have only just started my family. I got very depressed thinking of all the things I wouldn't be able to see - my daughter's first steps, my daughter walk down the aisle in her wedding dress, my grandchildren. I was aware of how many blind people struggle to find work and although I did not plan it, I had considered if my life insurance would be better for my family than the burden I felt I would become."

In October 2013, Mark wrote to the hospital and was told that lack of capacity in the eye clinic was to blame for the delay. The hospital said that the newly approved treatment "will result in a significant increase in activity for the hospital" and that "the eye clinic is very busy... the busiest clinic in the hospital." He was also told that "subject to final contractual issues, the treatment should be made available to DMO patients over the coming weeks" and that "patients will then be contacted to make appointments."

Mark finally contacted RNIB, who in turn sent a letter to the hospital trust pointing out its legal obligations to provide NHS patients with approved treatments. Mark has now been given further treatment, his vision has

improved and he says that his life is back on track.

Danielle Green, 45, Hull

Danielle was diagnosed with diabetes at 13. She had always been aware of the need to be careful with her eyesight and has regularly experienced problems getting appointments for diabetic retinopathy check-ups (especially during her pregnancies despite pregnancy creating extra risks for diabetics). These delays and cancellations have left her frustrated and worried.

When attending hospital appointments, Danielle says she is regularly told that she must be seen within three months. However, letters offering appointments are often delayed, if they arrive at all. Danielle says that in the past she has had to wait a whole year to be seen despite being told by the doctor to return in several months.

Danielle notes: "I constantly have to chase for appointments and I know that other people, less confident people, might not be strong enough to do all the chasing." She adds that: "Every time my eye bleeds, I'm at risk of losing more of the remaining sight I have left. I have three children and when I lose more sight, this impacts on them as well as on me."

Ronald Norris, 80, London

Ronald has been attending his local eye clinic for 35 years.

After being diagnosed with Glaucoma in 1997, Ronald was supposed to have regular appointments. However, they were often cancelled or postponed – sometimes he would not find out until he arrived at the hospital, which was very frustrating as it takes him a long time to get to each appointment. During the 35 years, Ronald has had cataracts removed from both eyes and a trabeculectomy (a surgical procedure used in the treatment of glaucoma to relieve pressure inside the eye).

In March 2013, he developed an eye infection and was referred to a large London hospital. There were problems transferring Ronald's medical notes and when it did happen he was sent a copy. He was very angry to see that the documents noted a 'failed' operation in his left eye. He had never been told there were problems and said that if he had realised this, he would have pushed for more treatment in his left eye and perhaps not ended up losing the sight in it. The sight loss has had a huge impact on Ronald's life and he has had to give up voluntary work, which he really enjoyed.

