How the APPG on Eye Health and Visual Impairment conducted the Inquiry into capacity problems in NHS eye care services in England

## Introduction

1.1 The purpose of the All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment is to inform and educate parliamentarians about the importance of high quality eye care for the prevention of eye disease, sight loss and blindness and for the eye health of the nation; and to promote better understanding of visual impairment and greater social inclusion. All-Party Parliamentary Groups are informal cross-party groups.

1.2 Our report “See the light: Improving capacity in NHS eye care in England” (June 2018), which is available at [www.rnib.org.uk/appginquiry](http://www.rnib.org.uk/appginquiry), highlights the findings and recommendations from our Inquiry into capacity problems in NHS eye care services in England.

1.3 We undertook our Inquiry because we were concerned about a growing problem of patients experiencing irreversible sight loss due to delayed and cancelled appointments. The 2017 British Ophthalmological Surveillance Unit (BOSU) study of all UK consultant ophthalmologists, found that up to 22 patients per month were suffering permanent and severe visual loss due to health service initiated delays.[**[[1]](#endnote-2)**] Research published by the Royal National Institute of Blind People (RNIB) had indicated that people were losing their sight unnecessarily because UK eye clinics were not keeping up with demand[**[[2]](#endnote-3)**].

1.4 This paper provides an overview of the Inquiry aims, objectives and scope, how evidence was collected and analysed.

## Resources and expert advice

2.1 RNIB and the Optical Confederation provide the secretariat to the APPG. We received additional support for our Inquiry from an independent secretariat hosted by RNIB. This was in part funded by Bayer a pharmaceutical company who had no role in the development, scope or delivery of the Inquiry.

2.2 An Expert Advisory Group provided us with advice and guidance about the analysis of evidence and development of recommendations. The Expert Advisory Group included patients volunteering with the Macular Society, International Glaucoma Association (IGA) and RNIB. It also included representatives from the College of Optometrists, Optical Confederation, Royal College of Ophthalmologists, Birmingham Focus, RNIB, Vision UK and NHS Alliance. The membership of the group is shown in the Annex.

## Aims, objectives and scope

3.1 The aim of the Inquiry was to investigate how capacity problems in NHS eye care services can be addressed. Our objective was to identify the barriers and opportunities in national and local health commissioning and planning to ensure that capacity will meet demand for eye health services to prevent avoidable sight loss.

3.2 The scope of the Inquiry was the commissioning and planning of eye care services at the national and local level within England. Specifically eye care service to detect and treat eye conditions for which there are effective treatments, which if not treated in a clinically appropriate time may lead to permenant sight loss.Conditions such as diabetic eye disease, glaucoma, wet Age Related Macular Degeneration (AMD).

3.3 The Inquiry did not include refractive error which can usually be corrected by glasses or contact lenses (e.g. short or long-sightedness), or support usually provided by social services for adults and children who experience sight loss.

## Methodology

### How evidence was collected

4.1.1 Evidence was provided to us through a patient survey, a call for written evidence and two oral evidence hearings held in Parliament.

### Patient survey

4.2.1 We ran an online and telephone patient survey for five-weeks between the 11th September and 20th October 2017. The survey gathered quantitative data about delays and cancellations, and qualitative data about the impact of delays and cancellations, what worked well, what didn’t work well, and suggestions for improvements from patients who had received treatment within the last three years, (not including the routine provision of glasses or contact lenses) about their experiences of eye care services in England. We received 557 eligible responses.[**[[3]](#endnote-4)**] Survey respondents were recruited from:

* RNIB’s existing communications channels and social media platforms and RNIB Connect Radio
* Other charities and networks including the Macular Society, the International Glaucoma Association, Seeability and other sight loss and health charities, as well as APPG Expert Advisory Group member organisations, and
* RNIB’s ‘research panel’ which includes people that have contributed to previous consultations on National Institute for Health and Care Excellence (NICE) guidance. RNIB draws upon this panel, of approximately 150 people with a sight condition, to engage in surveys and other research.

### Call for evidence

4.3.1 We published a call for evidence for twelve weeks from the 28th July until 20th October 2017, gathering written submissions from:

* Department of Health, NHS England and Public Health England
* Commissioners and NHS Eye Departments
* Sustainability Transformation Partnerships (STPs), and
* Health profession bodies, charities, research and health industry organisations with an interest in eye health and commissioning and planning
* Patients and their families.

4.3.2 The original intention was to take evidence from other areas of health policy (to identify any lessons that could be applied to eye health); but this was not taken forward due to the relatively large amount of evidence we received and the limited resource of the secretariat.

4.3.3 The call for evidence was emailed to organisations’ senior managers (e.g. Chairs and CEOs), reminder emails and phone calls to encourage responses. It was also advertised on social media via the APPG and RNIB twitter accounts, and other organisations were asked to publicise it on social media. We received 91responses on behalf of 112 organisations, plus written responses from a small number of individuals.

### Oral evidence hearings

4.4.1 We held two oral evidence sessions in Parliament on the 28th of November and 5th of December 2017. Patients using NHS eye care services and professionals involved in the provision of services, including clinicians, commissioners and other interested parties gave oral evidence to us.

4.4.2 Criteria for inviting people to give oral evidence:

* patients with experience of using NHS eye care services, both positive and negative experiences who have learning that may be more widely applicable to the NHS,
* professionals including practicing clinicians, commissioners, patient advocacy organisations, speakers with experience of current challenges, barriers and positive outcomes, and that may be more widely applicable to the NHS, and
* demographic and geographical diversity.

4.4.3 Once potential patient speakers were identified, the secretariat undertook preliminary interviews to understand people’s stories. Patients were sent notes on the key points they had raised to assist them with giving evidence within the time-constraints of their evidence session slot; but were free to raise whatever points they wanted to on the day.

4.4.4 Eight patients with a range of eye conditions from across a number of English regions; and three clinicians, a commissioner from a Clinical Commissioning Group (CCG), a manager from a local sight loss charity and the lead clinicians from the Getting It Right First Time ophthalmology programme provided oral evidence. We tried to secure the attendance of an STP but were unable to.

### Overview of the Inquiry’s evidence-gathering

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Respondent | Patient survey | Call for evidence (organisations or people) | Hearings | Total |
| Patient or patient representative | 557 | 9 | 8 | 574 |
| Commissioners, NHS Eye Departments, clinicians | 0 | 46 (65) | 4 | 50 (69) |
| Charities/ umbrella bodies | 0 | 10 (11) | 1 | 11 (12) |
| STPs | 0 | 7 | 0 | 7 |
| Professional bodies | 0 | 5 (6) | 0 | 5 (6) |
| Government/ national bodies/ initiatives | 0 | 4 | 1 | 5 |
| Healthcare/ pharmaceutical industry | 0 | 4 | 0 | 4 |
| Local Eye Health Networks | 0 | 4 | 0 | 4 |
| Local Optical Committees | 0 | 1 | 0 | 1 |
| Universities | 0 | 1 | 0 | 1 |
| **Totals** | **557** | **91 (112)** | **14** | **662 (683)** |

### Analysis

4.6.1 The secretariat collated the results of the patient survey and submissions to the call for evidence, and proposed to share the submissions in full with the Expert Advisory Group; or to summarise the evidence in a series of papers and present them to the group to consider. The latter approach was agreed, with the secretariat producing summary evidence papers to capture the range of respondents’ information and perspectives and to identify key trends and themes. The papers were grouped around particular questions (e.g. ‘assessing the eye health needs of local populations’) which were asked to different sectors. A written record of the oral evidence sessions was also produced. These papers have been collated and are available online at [www.rnib.org.uk/appginquiry](http://www.rnib.org.uk/appginquiry) .

4.6.2 Reviewing the evidence the Expert Advisory Group and the secretariat identified possible recommendations for inclusion in our report. The co-chairs of the APPG considered these suggestions and agreed the final recommendations from the inquiry. These recommendations are available in the final report at [www.rnib.org.uk/appginquiry](http://www.rnib.org.uk/appginquiry) .

## Publication of the report, implementation and monitoring of the recommendations

5.1 Our report “See the light: Improving capacity in NHS eye care in England” (June 2018), will be launched on the 6th of June at a Parliamentary reception attended by Parliamentarians, policy-makers and eye health sector stakeholders.The report is available at: [www.rnib.org.uk/appginquiry](http://www.rnib.org.uk/appginquiry) .

5.2 The recommendations in our report, when implemented, will help to ensure services are better able to meet increasing demand, improve the delivery of joined up eye care, and reduce the numbers of patients losing sight because of delay and cancelled appointments.

5.3 Members of the APPG and the Expert Advisory Group are keen to support those working on eye care policy and service delivery to help implement the recommendations, to make a positive difference for patients at risk of sight loss. We will seek to meet with the Secretary of State for Health and Social Care to discuss our report’s findings and we will be monitoring progress on implemention of its recommendations.

## Annex: The Expert Advisory Group

Susan Blakeney, College of Optometrists, Clinical Adviser

Mike Burdon, The Royal College of Ophthalmologists, President

David Hewlett, CEO, The Federation of (Ophthalmic and Dispensing)

Opticians / Optical Confederation

Susan Hoath, Chief Executive, Birmingham Focus

Malcolm Johnson, patient representative

David Quigley, patient representative

Michael Sobanja (Chair), NHS Alliance

Alan Tinger, RNIB Trustee/ Honorary Treasurer

Keith Valentine, Chief Executive, Vision UK

Stephen Vernon, Royal College of Ophthalmologists, Vice President

Christine Wall, patient representative

## Endnotes

1. **.** 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-2)
2. **.** RNIB (2013) “Saving money, losing sight”. [↑](#endnote-ref-3)
3. . We received approximately 650 initial responses to the patient survey. The survey data-set was subsequently ‘cleaned’ which involved removing those people who were outside the survey’s scope: that do not live in England, had not been treated within the last three years and who only answered the first one / two questions and then left the survey. We also removed respondents with self-reported eye health conditions who were outside of the Inquiry’s scope. The Vice President of the Royal College of Ophthalmologists and the Clinical Adviser to the College of Optometrists (members of the Expert Advisory Group) provided guidance on this. The Inquiry’s focused on eye care services for eye conditions for which there are effective treatments, which may lead, if not treated in the clinically appropriate time to a person becoming blind or partially sighted.

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