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Surveillance of sight loss due to delay in ophthalmic treatment or review

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1 **Surveillance of Sight Loss due to delay in ophthalmic treatment or**
2 **review: Frequency, cause and outcome**

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17 Conflicts of Interest: None

18 Purpose

19 To determine the frequency of patients suffering harm due to delay in
20 ophthalmic care in the UK over a 12-month period.

21 Methods

22 Patients with deterioration in vision in at least one eye of 3 lines of Snellen
23 acuity or 15 letters on ETDRS chart or deterioration in visual field deviation of 3
24 decibels due to health service initiated delay in review or care were
25 ascertained through the BOSU using prospective active surveillance involving
26 all UK consultant ophthalmologists. Demographic details, diagnosis, cause and
27 length of delay, and vision loss were then sought by questionnaire.

28 Results

29 238 cases reported between March 2015 and February 2016. 197/238
30 questionnaires were returned (83%). 28 reports were out of the study period
31 or did not meet the case definition. Median age was 76 years (range: 1 to 98
32 years). Median delay was 22 weeks (range: 2 days to 5 ½ years). 72%
33 experienced permanent reduction in visual acuity, 23% permanent
34 deterioration in visual field. Main diagnoses were Glaucoma 42%, Age-related
35 Macular Degeneration (AMD) 23% and Diabetic Retinopathy (DR) 16%. 18
36 patients were eligible for Severely Sight Impaired (SSI) or Sight Impaired (SI)

37 registration. Main causes were delayed follow-up (76%), lost referral (7%) and
38 delayed treatment (8%).

39 Conclusion

40 Patients are suffering preventable harm due to health service initiated delay
41 leading to permanently reduced vision. This is occurring in patients of all ages,
42 but most consistently in those with chronic conditions. Delayed follow up or
43 review is the cause in the majority of cases indicating a lack of capacity within
44 the hospital eye service.

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47 **Surveillance of Sight Loss due to delay in ophthalmic treatment or**
48 **review: Frequency, cause and outcome**

49

50 **Introduction**

51 The NHS aspires to provide high-quality care that is safe, effective and focused
52 on patient experience in pursuit of timely and compassionate care for every
53 person who uses and relies on its services. This is, and always has been,
54 determined by clinical need and free at the point of care (1). As part of this
55 there are published guidelines detailing expected timescales for ophthalmic
56 care and review which cover many common ophthalmic conditions. This
57 includes a patient's legal right to treatment within 18 weeks of referral (1). The
58 NHS is committed through its constitution to providing a comprehensive
59 service available to all that aspires to the highest standards of excellence and
60 professionalism whilst putting the patient at the heart of every decision (1),
61 however this does not include published NHS standards or commitment on the
62 length of time for follow-up appointments.

63 In 2009 the National Patient Safety Agency (NPSA) reported 44 glaucoma
64 patients who experienced deterioration of vision, including 13 reports of total
65 loss of vision, attributed to delayed follow up appointments over a 12-month

66 period (2). They reported a further 91 incidents related to delayed, postponed
67 or cancelled appointments for patients with glaucoma where the level of harm
68 was not known. A more recent review by the National Reporting and Learning
69 System (NRLS) of harm/ loss of vision, using the returns of the adverse event
70 reporting system, identified nearly 500 incidences of harm – loss or
71 deterioration of vision (27% severe harm and 73% moderate harm) in the 2
72 year period between 2011 and 2013 (personal communication).

73 These data were sourced through a generic cross specialty system and due to
74 their free text nature, the reports contained no specified definition of severe
75 or moderate and were unable to accurately determine the degree of sight loss,
76 the associated eye conditions or the demographic characteristics of the
77 affected patient population. However, they clearly describe the occurrence of
78 potentially unnecessary sight loss. This is a situation backed up by a growing
79 number of reported concerns from ophthalmologists based upon clinical
80 experience and news reports in the media (3). This study was undertaken to
81 provide a robust estimate of the number of patients suffering serious harm
82 due to delay in review or treatment, along with levels of recorded visual acuity
83 or field loss, patient demographics, diagnosis, as well as the cause and length
84 of the delay.

85

86 **Materials and methods**

87 Patients were identified prospectively using a system of nationwide active
88 surveillance through the British Ophthalmological Surveillance Unit (BOSU)
89 monthly reporting card system (4). All consultant or associate specialist
90 ophthalmologists with clinical autonomy in the United Kingdom form the
91 reporting base for the BOSU surveillance scheme. Each month they are sent a
92 reporting card by BOSU requesting them to report if they have seen in the
93 preceding month any patient with the conditions currently under surveillance.
94 The BOSU then informs the respective study investigators which
95 ophthalmologists have reported a case and the study investigators then
96 contact the reporting ophthalmologist.

97 For the 12-month study period between March 2015 and February 2016
98 inclusive, ophthalmologists were asked to notify the study investigators,
99 through the BOSU, of any of newly presenting patients who had sight loss due
100 to delay in review or treatment. The definition of harm due to delay was
101 defined as a deterioration of vision in at least one eye of 3 lines of Snellen
102 acuity (or 15 letters on the ETDRS chart) or deterioration in the visual field of 3
103 decibels or patients whose vision has deteriorated to below that measured on
104 the Snellen Chart to Counting Fingers or worse due to a health service initiated

105 delay in ophthalmic review or care. Delays caused by the patient's failure to
106 attend (DNA) were not included.

107 Reporting ophthalmologists who notified the BOSU of a case were sent a
108 questionnaire that sought information on the patients age, gender, ethnicity,
109 diagnosis, cause and length of delay and deterioration in vision.

110 Ophthalmologists who did not return the questionnaire were sent a reminder
111 letter to increase the response rate.

112 To improve the accuracy of the estimate of frequency, duplicate reports in the
113 absence of any patient identifiers were recognised using probability matching
114 of age, hospital, and date of appointment after delay.

115 This study was given approval by the NHS Fife R&D department in January
116 2015.

117 Data were recorded in a Microsoft Access database. VA data were collected as
118 recorded in the hospital notes, loss of vision was calculated using the raw data
119 before being converted into lines on a Snellen chart equivalent.

120 **Results**

121 238 cases were reported to the BOSU during the 12 month study period and
122 197/238 questionnaires were returned (response rate 83%). In total 28 case
123 reports were subsequently excluded from the study (4 duplicate reports, 11

124 did not meet the threshold for sight loss detailed in the case definition and 13
125 referred to patients presenting before the study period). 169 confirmed cases
126 meeting the case definition during the study period were identified.

127 **Patient demographics**

128 The median patient age was 76 years with a range of 1 year to 98 years. The
129 distribution by life stage is shown in table 1.

130 54% of the patients were male and 93.4% recorded their ethnicity as White,
131 1.8% as Asian and 4.8% as Black.

132 **Diagnosis and visual loss**

133 The most frequent diagnoses were chronic conditions that required regular
134 follow up (figure 1)

135 There were incomplete visual data for 26 patients. For the 106 patients with a
136 reported loss of acuity there was a median loss of the equivalent of 4 Snellen
137 lines of acuity (range 1 to 9 lines) (table 2). Patients reported to have a loss of
138 less than 3 lines either had an acuity of CF or worse or had associated field loss.

139 Comparative visual field data were available for 46 patients. The median loss
140 was 7 decibels with a range of 2 to 20, and 23 patients with a loss of greater
141 than 8 decibels.

142 132 patients experienced a permanent deterioration in vision. 98 had
143 permanent loss of acuity, 28 had permanent deterioration in visual field, and 6
144 had permanent deterioration in both acuity and visual fields. 13 patients were
145 reported to have suffered a temporary loss of vision due to their delay in
146 treatment or review but, of these, 9 required an unplanned surgical procedure.
147 In addition, 6 patients with permanent deterioration in vision required an
148 unplanned surgical intervention and 6 patients required to be admitted to
149 hospital as an emergency. Twenty patients were reported to be eligible to be
150 registered as severely sight impaired (blind) and 22 as sight impaired (partially
151 sighted).

152 **Cause and length of delay**

153 The main cause of delay (80% of cases) was a follow-up appointment that
154 occurred beyond the clinically recommended time. (figure 2).

155 The median delay beyond the intended follow-up period was 22 weeks with a
156 range of 2 days to 5 ½ years, with 26 patients experiencing a delay of over 12
157 months. The proportionate delay as a multiple of planned follow-up (actual
158 follow-up time/ planned follow-up time) is shown in figure 3. The median was
159 2.8 times the planned follow-up time, with a range of 1.07 to 71 times.

160

161 **Discussion**

162 This study demonstrates, through nationwide prospective data collection, that
163 patients who are within the hospital eye service are losing vision because of
164 delays in their intended care. The main cause was a delayed follow-up
165 appointment beyond the clinically recommended interval, which occurred in
166 80% of affected patients. The majority of patients had chronic conditions
167 requiring continuous long term follow-up, similar to that reported at
168 Moorfields Eye Hospital (5) and this is likely to indicate an association between
169 patient need and lack of health service capacity. The commonest reported
170 diagnosis was glaucoma, a condition for which delayed follow up has
171 previously been reported as a preventable cause of loss of vision (6,7). Within
172 the context of an aging population, in which the estimated prevalence of
173 glaucoma increases from 0.3% in the 40 – 50 year olds to 3.3% in those over 70
174 (8), demand upon the health service to provide care continues to increase.

175 At present, in contrast to appointments and treatment following initial (or
176 new) referrals there are no targets or penalties imposed for hospitals that
177 delay or re-book follow-up appointments to beyond the time interval
178 recommended by the clinician. It is probable, and recognised by clinicians, that
179 due to the requirements to meet the 18 week referral to treatment targets
180 (RTT), hospitals are prioritising new referrals over reviews (7). This is despite

181 review patients being significantly more likely to have confirmed pathology
182 that may lead to vision loss and as demonstrated, delays for follow-up patients
183 are resulting in this form of harm.

184 The number of cases reported in this study represents the minimum frequency
185 during the defined study period. Cases for this study were ascertained through
186 a well-established surveillance methodology shown to be effective (9, 10) and
187 to work in the UK healthcare context (4). However, it is probable that there is a
188 degree of underascertainment. Previous reports for studies identifying cases
189 through the BOSU have indicated that ascertainment rates usually lie between
190 65% and 95%.(4,11).

191 Although not directly linked to ascertainment, response rates are the most
192 common method for assessing underascertainment (9). Higher response rates
193 do correlate with better overall ascertainment (12), which means that the
194 BOSU card return rate of 76% and the questionnaire return rate of 83% during
195 the study period indicate high levels of compliance. This suggests that this
196 study's ascertainment was in line with other previous BOSU studies. Adjusting
197 for underascertainment would provide a potential likely frequency of between
198 178 and 260 cases per year (between 15 and 22 cases per month in the UK).

199 The BOSU reporting scheme is dependent on voluntary reporting and there is
200 evidence of good compliance from reporting ophthalmologists. However, the
201 effects of systematic under-reporting should be considered, for example where
202 reporting cases may have been perceived to affect the reputation and future
203 care provision within an organisation, despite the investigators clearly stating
204 that all data would be amalgamated before being published.

205 The NRLS estimated approximately 250 cases of harm due to delay per year
206 (personal communication). This is a similar figure to one we report; however, it
207 should be noted that their estimates were based upon adverse event reporting
208 and there were no predetermined definitions of harm beyond the reporters'
209 own perception of the terms moderate and severe. We have ensured that
210 those patients reported had suffered significant deterioration of vision beyond
211 any level that might be an artefact of measurement or that which would be
212 expected were standard care provided. We have therefore identified a genuine
213 source of otherwise preventable iatrogenic sight loss. This study did not
214 attempt to measure the less explicit levels of harm. However, Davies identified
215 16 cases of harm occurring in 12 316 lost to follow-up clinical reviews (8). This
216 further suggests that those identified in this study are drawn from a much
217 larger population of patients being placed at risk of significant harm or
218 unfavourable prognosis due to health service initiated delays.

219 In this study 42 patients were reported to have become eligible for sight
220 impairment (partial sight) or severe sight impairment (blind) registration
221 following a delay in review or treatment. Previous models of costs and
222 outcomes have illustrated the financial benefit of preventing vision loss and
223 blindness which is estimated to amount to £28 billion per year in the UK (13).
224 However, patients are suffering preventable harm due to health service
225 initiated delays and this is leading to permanently reduced vision – a problem
226 that has been recognised for nearly 15 years. Whilst this is occurring in patients
227 of all ages, it is most consistent in those with chronic conditions associated
228 with aging. In common with previous reports, we have been able to identify
229 that delayed follow up appointments are the cause in the vast majority of
230 cases indicating a lack of capacity. The data from this study are limited to a
231 cross-sectional description but reaffirms the need for consistent robust
232 surveillance systems to monitor patients and the subsequent potential health
233 benefits to provide information on trends. (5,6)

234 It is recognised that loss of vision impacts negatively on both physical and
235 mental health – those with sight loss are more likely to suffer falls (14),
236 depression(15) and to become dependent on social services at an earlier stage.
237 For children poor vision may lead to a lifetime of difficulty in reaching full
238 potential as well as educational and developmental challenges. For those in

239 the working age group, poor vision commonly precludes meaningful
240 employment (16). It is extremely concerning that patients who are within the
241 hospital system are losing vision because they are not receiving the care they
242 need in a timely fashion.

243 The solutions lie in making collection and reporting of the intended follow up
244 date of outpatient appointments compulsory, optimising capacity in
245 ophthalmic out-patient departments and empowering patients to challenge
246 delays (17).

247 The collection of data on the difference between the actual and intended
248 appointment date will highlight individual patient delays and measure the
249 shortfall in overall capacity across, not just ophthalmology, but all specialties to
250 identify capacity deficits and where resources, systems and patient care could
251 be improved. This would also improve individual patient safety as alerts to
252 unsafe delays would be evident.

253

254

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256

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