National Patient Safety Agency

National Reporting and Learning Service

Rapid Response Report NPSA/2009/RRR004: Preventing delay to follow up for patients with glaucoma

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Supporting Information

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NOTE: this supporting information is intended to be read with Rapid Response Report: Preventing delay to follow up for patients with glaucoma. www.npsa.nhs.uk/patientsafety/alerts-and-directives

Gateway reference: 11994

Introduction

The National Patient Safety Agency (NPSA) has issued guidance on Preventing delay to follow up for patients with glaucoma [NPSA/2009/RRR004]. This follows evidence of harm to patients with glaucoma suffering visual loss after delays to follow up appointments.

This came to light from incidents reported by staff in the NHS relating to glaucoma but there are general issues in terms of strengthening systems for monitoring other chronic conditions. The NPSA will continue to monitor reports relating to other clinical conditions and harm resulting from failure to follow up as clinically indicated and would encourage all staff to report these as patient safety incidents.

Key messages of this Rapid Response Report

- **Treating clinicians should ensure that all people with ocular hypertension or suspected or diagnosed glaucoma are monitored within the monitoring intervals outlined in the NICE glaucoma guideline and that,**
- **None of these monitoring appointments should be delayed or cancelled**

This paper provides background information and a checklist for organisations to help implement actions in the accompanying guidance to prevent harm from delayed follow-up appointments for patients with glaucoma. It presents details of incident data and litigation data; other evidence is provided in the comprehensive NICE guidelines.[1] This NPSA

work was supported by an interactive event in March 2009 with input from ophthalmic surgeons (and the Royal College of Ophthalmologists), nurses, service managers and patient representatives.

It is anticipated that the Rapid Response Report and this accompanying supporting information is for commissioners and acute Trusts to action but should also be made available to other groups such as hospital and community optometrists.

Background

Primary open angle glaucoma is a progressive and potentially blinding eye disorder. Early detection of glaucoma is important to prevent severe visual loss later in life. Once diagnosed this condition requires life long management and evidence from clinical trials indicates that reduction in intra ocular pressure (IOP) can significantly delay disease progression.[2] Suspect glaucoma accounts for a large percentage of new referrals to the Hospital Eye Services (HES) (16-20%) and an even larger number of return visits because of the so called 'snowball effect' (25-30%).[3]

Glaucoma management has evolved rapidly with several models and care pathways. In the past ophthalmic services have been almost always provided by HES based clinical teams. More recently, plurality of service providers for some ophthalmic services now exists. Other care providers such as optometrists,[4,5] specialist nurses [5] and general practitioners with a special interest in glaucoma may now share the care of glaucoma patients. Such models of care are based on the assumption that community optometrists have the background knowledge, skills and

instrumentation required for carrying out clinical measurements applicable to glaucoma. With suitable training such practitioners may have a role in undertaking some glaucoma assessments currently performed by hospital staff.[6] The Bristol Shared Care Glaucoma Study [7] compared a model of shared care with routine HES follow up and concluded that there were no significant differences in outcome between patients followed up in the HES or by community optometrists in their model.

Scale of the patient safety issue

A trigger incident was reported by a trust to the Reporting and Learning System (RLS), where a patient suffering with glaucoma had their follow up appointment delayed and as a result of the ensuing delay in review there was deterioration in the patient's vision. An expert clinical opinion was sought from the Chairman of the Royal College of Ophthalmologists Quality and Safety Sub-Committee who confirmed the problem and consequently a focussed RLS search was undertaken.

Data from the Reporting and Learning System (RLS) [1]

Analysis of the RLS data revealed 135 patient safety incidents received by the NPSA between June 2005 and May 2009 reporting delayed, postponed or cancelled appointments. 44 incidents were reported where it is explicitly stated that due to delays in a follow-up appointment a

[1] *The NPSA's Reporting and Learning System (RLS) was established to provide a national database of incidents relating to patient risks and harm. Interpretation of data from the RLS should be undertaken with caution. As with any voluntary reporting system, the data are subject to bias. Many incidents are not reported, and those which are reported may be incomplete having been reported immediately and before the patient outcome is known.*

patient has suffered (in some cases severe) deterioration in vision including 13 reports where there has been a loss of vision.

Although predominantly reported from the hospital out-patient setting, 4 were reported from primary care settings including one from an optometrist. 12 were reported from an in-patient setting. It is not possible to determine the staff type of the reporter. Examples of such incidents include:

Fairly advanced Glaucoma. Last seen October 2005. Follow up appointment booked for 6 month. No follow up sent due to backlog which has been repeatedly brought to the attention of the management for the past 18 months. Patient was only seen as follow up was chased up by renal physicians. The patient's intraocular pressures 38mmHg right eye and 35mm Hg left with further visual field loss. This could have been prevented.

Patient suffered from Glaucoma and was last seen on 8 / 9 / 06 in clinic. She had tear duct procedure done on 22 / 1 / 07 and then a 4 month follow up appointment was made. But she never received any appointments and seen by an optician on 15.3.08 and who found her intraocular pressure was high. She was seen today and her pressure was high in both eyes.

Requested 3 month glaucoma follow - up appointment delayed to 7 months. During this delay the patient has lost further vision.

A summary of the RLS data findings was forwarded to NICE by the NPSA as part of the consultation process for their recently issued guidance on this condition.

NHSLA Data

A review of the data from the National Health Service Litigation Authority (NHSLA) revealed one case in litigation reportedly relating to glaucoma. The incident related to an alleged delay in treating an acute angle closure glaucoma event.

Other Evidence

Problems have been covered in the media, for instance it was reported that over 1000 appointments a month were cancelled at the Bristol Eye Hospital with some patients waiting 20 months longer than the planned date of their appointments. Twenty five patients, mostly those with glaucoma or diabetes lost their vision during the wait.[8] One of the patients, an elderly lady whose follow up appointments for glaucoma were delayed several times became totally blind as her glaucoma deteriorated during the wait.[9]

On 22 April 2009, NICE issued guidance on best practice on the diagnosis and management of chronic open angle glaucoma and ocular hypertension.[1] NICE glaucoma support tools can be found at http://www.nice.org.uk/guidance/CG85. These include patient versions of the guidelines, as well as the full guidelines for clinicians. In addition, NICE will publish audit criteria in July 2009 and a commissioning guide in September 2009.

Summary and conclusion

The RLS data indicates significant levels of harm for patients because of failures in systems to ensure timely follow up of a serious clinical eye condition. Of the 135 relevant incidents in the RLS there are examples of patients who have lost their sight or suffered deterioration in their vision because appointments are postponed, cancelled or patients are not put into the follow up system at all. The reports also indicate that in a number of cases if follow-up appointments had been kept then treatments might have been instigated to lessen the harm caused.

The recently issued guidance from NICE entitled 'Glaucoma: diagnosis and management of chronic open angle glaucoma and ocular hypertension' sets out best practice on the diagnosis and management of open angle glaucoma and ocular hypertension including optimal treatment and follow-up standards. This Rapid Response Report (RRR) is intended to complement the NICE guidance by urging NHS organisations to review their systems and processes to minimise the risk of avoidable sight loss for patients with established or suspected glaucoma. This review should include assessing the capacity within the ophthalmic service, reviewing the robustness of booking systems to ensure they are able to respond to clinical priorities and the provision of information to patients.

Appendix 1: Suggested rationale and compliance checklist

Commissioners will be interested in the final column of the table below relating to suggested evidence for local assurance of compliance. It is anticipated that this Rapid Response Report may stimulate further dialogue between commissioners and providers about service provision. As a starting point, commissioners can use evidence on delayed or cancelled follow-up appointments for patients with glaucoma as part of a needs assessment plan. Further work may be needed to map needs against capacity and consider how best to provide services, as part of the Commissioning for Quality and Innovation (CQUIN) framework.

Action	Rationale	Suggested evidence for local assurance of compliance
1. Make NICE guidelines on glaucoma available to all relevant staff and develop an action plan to implement the recommendations.	Clinical and service management personnel should develop joint action plans based on the NICE guidelines to ensure the optimal standards for clinical care are achieved.	Dated record of electronic and / or hard copy distribution lists. Copy of jointly developed action plans based on the NICE guidelines with record of submission to the relevant clinical governance forum for implementation support and compliance monitoring.
2. Review levels of hospital-initiated cancellation of appointments rates for patients with established or suspected glaucoma through clinical governance forums.	An accurate baseline picture of the numbers and, where possible reasons for, hospital initiated cancellations is essential to inform any corrective action needed. A period of twelve months is suggested.	Copy of an analysis of cancellations with record of submission to a clinical governance forum for clinical / service management discussion.
3. Review patient 'did not attend' rates in order to identify	An accurate baseline picture of the numbers of patients who have not	Copy of an analysis of patient 'did not attend' rates with record of

and audit high risk patients who ' did not attend'.	attended appointments is essential to identify those at high risk and to inform any corrective action needed. A period of twelve months is suggested.	submission to a clinical governance forum for clinical / service management discussion.
4. Identify the number of patients currently awaiting follow-up and confirm that there is sufficient capacity within the local health community to meet this number in terms of outpatient appointments and any specialist investigations e.g. visual field and optic disc imaging.	An accurate picture of service demand and provision in essential to assess how the NICE guidance can be achieved. *Some reports to the RLS suggested that follow ups were routinely offered far beyond the original clinically intended intervals because of ongoing lack of capacity in local service.*	Copy of an analysis of current service level provision to meet the needs of the local health community in light of NICE guidance, with record of submission to the appropriate management and service commissioning forums.
5. Develop a system whereby patients can be 'flagged' on the booking/ appointment system to indicate the clinical priority given to the appointment and monitor activity to ensure compliance with NICE follow-up intervals	The development of a flagging system determined by clinical need may contribute to the avoidance of excessive review intervals and ensure that appointment postponements are an exceptional occurrence. *Reports submitted to the RLS suggested that follow ups which had been moved far beyond the original clinically intended intervals – e.g. a one month follow up*	Records indicating this system has been developed and a timed plan for implementation. Records of action taken when review appointment intervals exceed intended levels.

	moved to eleven months – but this was not recognised until the patient actually attended. *It is acknowledged that a delay in follow up from e.g. 4 to 5 months may not be critical but the major concern is from repeated cancellations or postponements of patients.* *The definition of what constitutes a reasonable tolerance for the difference between intended and actual follow-up may be considered in the future by the Royal College of Ophthalmologists as part of their work on national quality standards.*	
6. Make information on glaucoma available to patients and ensure that there is a straightforward process for patients to reschedule appointments where necessary.	NICE guidance requires patient information materials to be made available in a variety of media to assist informing patients of their condition and the importance of regular follow up appointments. An easy to access system to adjust appointments will contribute to patients rebooking rather than not attending an appointment.	Copy of locally supplied patient information, (based on material available from e.g. IGA and RNIB materials as well as patient version of NICE guidelines) including a clearly and easy to access system for patients to amend / re book appointments. Results of a patient survey or documentation audit indicating this information is consistently supplied.

	Some reports to the RLS suggested patients who did not receive a follow up appointment when expected did not know who to contact, or did not realise their follow up appointments were important.	

References

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