Improving the communication pathway for eye screening in paediatric diabetes

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Abstract
Diabetic retinopathy is a leading cause of vision loss in young adults. Current National Institute for Health and Care Excellence guidelines require that all children aged ≥12 years with diabetes are offered retinal screening annually. A local 2009–2010 audit identified that 57% underwent screening but only 16% had results documented with the paediatric diabetes service, highlighting areas for improvement. In 2011, the paediatric diabetes service formulated a standard operating procedure with the eye screening programme to improve referrals, screening and data collection.

We undertook a retrospective analysis of paediatric diabetes patients aged ≥12, attending a large paediatric diabetes service from April 2012 to April 2013.

Out of an eligible 268, evidence of referral was available for 259 and nine had no data. A total of 241 (90%) had results recorded for submission to the National Paediatric Diabetes Audit (NPDA). The remaining 18 had screening but paediatric services had no recorded data. In all, 256 attended screening and three patients did not attend, thus giving a 96% screening rate (256/268). Of 251 with gradable images, 18 patients (7.2%) had retinopathy. Those with retinopathy had higher HbA1c (85mmol/mol) than those without (73mmol/mol); P=0.011. No correlation was found with age of diagnosis or duration of diabetes.

Improvements in screening rates from 57% to 96%, recording rates from 16% to 90% and a 96% local screening rate compared to a 49.7% national screening rate (NPDA 2012–2013) clearly demonstrate the effectiveness of collaboration between services and of a structured clinical pathway. The findings also confirm retinopathy is more prevalent in children with diabetes with poor glycaemic control, underlining the importance of improving glycaemic control.

Key words
diabetes; children and young people; eye screening; clinical pathways

Introduction
Diabetic retinopathy is one of the leading causes of blindness in the developed world’s working age population.1 Screening for diabetic retinopathy is crucial as early detection and management are proven successful in reducing visual damage progression and prevent more than 90% of visual loss.2,3

Background retinopathy occurs in up to 29% of the adolescent type 1 diabetes population.4 The adolescent population is at greater risk of progression to vision-threatening retinopathy compared to adults.5 Glycaemic control influences the development and progression of diabetic retinopathy.6

Achieving optimal glycaemic control in children and young people is challenging. In 1997, the Hvidøre Childhood Diabetes Study showed that the mean HbA1c across 18 countries in Europe, Japan and North America was 70mmol/mol (8.6%) and only one-third had an HbA1c more than 64mmol/mol (8%).7

In England and Wales, the minority of children and young people have optimal glycaemic control, as only 15.8% have an HbA1c <58mmol/mol (7.5%) in the National Paediatric Diabetes Audit (2012–2013).8 Recent endeavours to improve glycaemic control include the Paediatric Diabetes Best Practice Tariff Standards and the National Children and Young People’s Diabetes Peer Review Programme outlining a comprehensive package of care.

In accordance with NICE guidance (CG15),9 children and young people aged 12 or over with diabetes mellitus should be offered annual eye screening. They form part of the defined population for the NHS Diabetic Eye Screening Programme (NDESP), a systematic population-based screening programme across England.10 While paediatric diabetes services are not
directly responsible for eye screening, they are required by NICE guidance and the Peer Review Programme to ensure eye screening is offered to their population; and they are required to submit eye screening data to the National Paediatric Diabetes Audit.

Implementation of standards is challenging, as evidenced by the National Paediatric Diabetes Audit (2012–2013), where only 49.7% of paediatric diabetes patients aged 12 or over in England and Wales attended eye screening. In contrast, the NDESP programme reports screening of 80.2% of the predominantly adult diabetes population.\(^5\)\(^,\)\(^10\) In paediatric diabetes, there is awareness of eye screening relevance, but the lower screening figures may reflect practical challenges of joined-up communication across organisations responsible for different elements of the clinical pathway. The emphasis of the NDESP communication interface is with primary care and service users. However, diabetes care for young people is commissioned from secondary care paediatric diabetes services. Without clear communication, the team providing a young person with the majority of their diabetes care will be unaware of the eye screening outcomes relevant for discussions on goal setting for an individual’s diabetes control.

**Aims**

- To assess if all eligible paediatric patients with diabetes aged 12 years or more are referred for diabetes eye screening.
- To assess the uptake of eye screening in those patients who are referred.
- To analyse the eye screening data for the clinic population, e.g. the proportion with evidence of diabetic retinopathy, any correlation between the presence of diabetic retinopathy factors such as gender, age, duration of diabetes and glycaemic control (HbA1c data).

**Methods**

The Bristol and Weston Paediatric Diabetes Service is a large paediatric diabetes service (479 patients) in South West England, providing outpatient services across five locations. Within the paediatric service’s region, the majority of patients attending general practices receive diabetic eye screening from one provider (Bristol and Weston Diabetic Eye Screening Programme). A few paediatric patients attended primary care practices, receiving their screening from adjacent regions’ eye screening services.

The first audit on patients aged 12 years or older covered the 12-month period of 1 September 2009 to 31 August 2010. Data were obtained from the paediatric diabetes service register (Access database), the eye screening database (Orion) from the Diabetic Eye Screening Programme and patients’ notes. The data collected included evidence of referral, screening attendance, screening results (graded according to national criteria),\(^11\) and evidence of results reaching the paediatric diabetes register.

Findings from the first audit prompted establishment of a Task-and-Finish Working Party involving administrative staff and a medical consultant from both the paediatric diabetes service and the eye screening service. Action points to solve identified process issues were agreed and reviewed quarterly. A standard operating procedure (SOP) was developed to clarify the pathway of responsibility for referrals, screening and data sharing and collection for all staff involved.

To assess efficacy of the practice change, we conducted a second audit examining 1 April 2012 to 31 March 2013. The second audit cycle was more detailed, collecting demographic data, age at diabetes diagnosis, duration of diabetes and most recent HbA1c; and we contacted primary care for patients with no eye screening information.

Data were analysed using Microsoft Excel. Statistical analysis compared the relationship between retinopathy, gender, HbA1c, diabetes duration and age at diagnosis. Statistical analysis of the variables HbA1c, diabetes duration and age at diagnosis was assessed using independent 2 tailed t-tests. Statistical analysis of the relationship between gender and the presence of retinopathy was carried out using Fisher’s exact test.

**Results**

**Baseline findings (first audit)**

The first audit of data, from September 2009 to August 2010, identified that 77% of eligible patients (i.e. 12 years or older) had been referred for retinal screening and 57% had attended screening. Of those referred, only 16% had a result received back from the eye screening service to the paediatric diabetes service. Of those who attended screening, 7% had background retinopathy in one or both eyes.

**Standard operating procedure (SOP) document**

The SOP outlined the process of referral to the eye screening service (agreed email proforma, prompts for the diabetes service staff to refer the young person to the eye screening service, either once the patient turned 12 years old or upon diagnosis of diabetes if this was over 12 years). The SOP also outlined mechanisms to prompt the screening service to send screening results to the paediatric service (in addition to primary care), including information on appointments not attended, and prompts for the paediatric diabetes administrative staff to chase missing screening information prior to each paediatric diabetes clinic appointment.

**Referral, attendance and reporting (second audit cycle)**

In the second audit cycle period (1 April 2012 to 31 March 2013), 479 children and young people received care with the paediatric diabetes service, of whom 282 were aged 12 or over. Fourteen of these patients were excluded as they had transitioned to adult services before the audit period end date. Of the 268 eligible: 259 (97%) had evidence recorded in the paediatric diabetes database of referral for retinal screening; 241 (90%) patients had attended screening with results recorded on the paediatric diabetes database; 18 (6.7%) had attended screening but results were not reported to the paediatric diabetes service (14 of these had
results sourced from the Bristol eye screening database and four sourced from their GP practice, as they attended an adjacent eye screening service; and three (1%) failed to attend any eye screening appointment within the audit period. There were nine (3%) patients eligible for screening, but for whom no evidence from the paediatric diabetes database, the eye screening database or GP records indicated either referral or screening. Figure 1 highlights the patient numbers in the second audit cycle.

**Eye screening findings (second audit cycle)**

Of the 256 patients screened, five had ungradable images leaving 251 with adequate images, of which 18 showed retinopathy (7.2%). Seventeen showed background retinopathy in both eyes and one had background retinopathy in the right eye only. This retinopathy group had a statistically significant higher HbA1c compared to those without retinopathy, although a similar age of diagnosis of diabetes and duration of diabetes (detail in Table 1).

**Comparison of pre- and post-SOP**

Between the 2010 and 2013 audits, quality improvement work was undertaken, including the introduction and implementation of the SOP document. Referral of patients for eye screening improved from 77% in 2011 to 97% in 2013, and the number of patients with retinal screening results reported to the paediatric diabetes service improved from 16% to 90% (as shown in Figure 2).

**Discussion**

Our study describes an effective Quality Improvement Project, developed due to identification of patchy and poor eye screening levels. In fact, an initial earlier snapshot audit in 2009 showed that the paediatric diabetes team were informed of eye screening for only 4% of eligible patients (unpublished data). This prompted raising team awareness of the eye screening requirements for our patients and
Eye screening is a key care process required to ensure quality of care for young people with diabetes. Early complication detection facilitates earlier treatment which can reduce or avoid morbidity. (At present, diabetic retinopathy is one of the leading causes of vision loss in the working age population)

The National Paediatric Diabetes Audit (NPDA) emphasises the importance of comprehensive care processes. The NPDA 2012–2013 indicates that just under half the children and young people with diabetes ≥12 years across England and Wales have eye screening reported to the NPDA.

Translating national recommendations into day-to-day clinical service is challenging. Audit indicates proportions meeting standards, but does not necessarily identify obstacles. Significant change requires analysis and implementation of a quality improvement approach

Eye screening services and paediatric diabetes services are separate organisations. So establishing close collaboration and dialogue between the services develops more effective communication and processes

Development of a standard operating procedure (SOP) clarifies eye screening pathway logistics. SOP implementation greatly increased both actual eye screening rates and results recording. We recommend services adopt this approach to address local issues, as effective collaboration improves delivery of care and outcomes for young people with diabetes.

### Key points

- Eye screening is a key care process required to ensure quality of care for young people with diabetes. Early complication detection facilitates earlier treatment which can reduce or avoid morbidity. (At present, diabetic retinopathy is one of the leading causes of vision loss in the working age population)
- The National Paediatric Diabetes Audit (NPDA) emphasises the importance of comprehensive care processes. The NPDA 2012–2013 indicates that just under half the children and young people with diabetes ≥12 years across England and Wales have eye screening reported to the NPDA.
- Translating national recommendations into day-to-day clinical service is challenging. Audit indicates proportions meeting standards, but does not necessarily identify obstacles. Significant change requires analysis and implementation of a quality improvement approach.
- Eye screening services and paediatric diabetes services are separate organisations. So establishing close collaboration and dialogue between the services develops more effective communication and processes.
- Development of a standard operating procedure (SOP) clarifies eye screening pathway logistics. SOP implementation greatly increased both actual eye screening rates and results recording. We recommend services adopt this approach to address local issues, as effective collaboration improves delivery of care and outcomes for young people with diabetes.

### References